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THE EXPERIENCE OF FEMALE SPOUSES OF CHRONIC LOW BACK PAIN SUFFERERS

BY

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©

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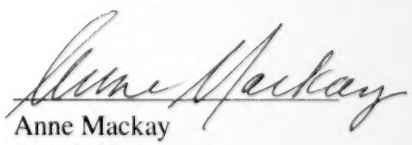

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF FEMALE SPOUSES OF CHRONIC LOW BACK PAIN SUFFERERS submitted by ANNE MACKAY in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY in COUNSELLING PSYCHOLOGY.

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DEDICATION

This dissertation, which represents the culmination of years of juggling multiple responsibilities and interests, is dedicated to Kim, Jeff, Kate, Joce, Ron, Wendy, Ronn, Thora, Bob, Susan, Bob, Cheryl, Ceinwen, Michelle, Marnie, Kathy, and Sharon for either encouraging, supporting, tolerating, providing, inquiring or just plain caring. There is no such thing as a self-made person.

ABSTRACT

The experience of female spouses of chronic low back pain (CLBP) sufferers was investigated using concept mapping, a blend of qualitative and quantitative methods. In Phase One, 14 spouses contributed 70 statements, which while predominately negative, included extreme disruption as well as neutral and positive experiences. In Phase Two, 21 female spouses sorted the 70 statements into homogenous groups. The sorted data were analyzed using concept mapping techniques to produce a map that consisted of seven themes: Depression/Isolation, Coping, Severe Couple Disruption, Focus on Pain Sufferer, Countercoping, Pain Focus, and Relationship Disruption. Further interpretation divided these seven clusters into two groups: mediators or consequences of pain. In Phase Three, 71 participants rated the 70 original statements, of which, 24 were determined to be common and/or prominent. Spouses most commonly experienced frustration because they could not do anything about their partner's pain, had a difficulty looking to the future, dealt with situations one day at a time, learned to do things differently and learned patience and compassion for others.

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CHAPTER 1: INTRODUCTION

Statement of the Problem

Chronic low back pain (CLBP) is a severe health and economic problem that affects a large portion of the population (Turk & Flor, 1984; Birse, 1994). CLBP accounts for high compensation and medical costs (Sternback, Wolf & Murphy, 1974; Webster & Snook, 1990; Girolamo, 1991; and personal communication with Macleod, 1996), high rates of lost work days (Back Association of Canada, 1988; Bonica cited in Girolamo, 1991) and is a leading cause of physical limitation and disability (United States Vital and Health Statistics, 1974).

In addition to the tremendous societal burden, an enormous emotional cost is born by individuals and family members (Brockopp & Brockopp, 1990; Turk, Flor & Rudy, 1987). CLBP sufferers tend to experience functional disability (Carron, 1985) that may include employment loss and reductions in physical and social activity (Subramanian, 1991). Emotional concomitants of CLBP are dependency, anger, guilt, fear, anxiety, hopelessness, and depression (Turk & Holzman, 1986).

Spouses are adversely impacted in a number of ways by chronic pain in a family member. In a 1987 review, Flor, Turk and Scholz concluded that spouses most frequently experience dysphoric mood, marital dissatisfaction, and physical health problems. Depression was reported by 25% (Flor, Kerns & Turk, 1987) and 28% of spouses (Schwartz, Slater, Birchler & Atkinson, 1990).

Several researchers noted the presence of marital problems in chronic pain populations (Feinauer & Steele, 1992; Roy, 1989a; Flor, Turk & Scholz, 1987; Roy, 1985a, 1985b; Kerns & Turk, 1984). Marital problems include sexual dysfunction in 84 to 91% (Maruta, Osborne, Swanson & Hallwig, 1981; Payne & Norfleet, 1986), and a disruption of roles, communication patterns, and family activities (Roy, 1989a; Subramanian, 1991).

The suggestion by Block (1981) and Block and Boyer (1984) that observation of spouses in pain may lead to physical symptoms in the spouse is supported by Rowat and Knafl (1985) in that 83% of spouses reported significant health problems which they attributed directly to chronic pain in their spouse. An increase in pain symptoms in the spouse is also reported by Mohamed, Weisz and Waring (1978) and Flor, Turk and Scholz (1987).

With the exception of Rowat and Knafl (1985), who combined semistructured interview with two self-report measures, research assessing the impact of chronic pain on the spouse has typically relied on the use of standardized, objective self-report measures. While much has been learned using self-report measures there are limitations connected with it. Self-report measures, while efficient, may be limited in their scope of inquiry. Thus the domain of experience of spouses of chronic pain patients may remain untapped. A second problem is that this type of research exemplifies the investigation of constructs as defined by researchers, rather than constructs as experienced by participants (Patton & Jackson, 1991). The investigation of the experience of the spouse of chronic pain patients has been constrained by researchers' previous conceptions and the instruments' limited range of construct assessment. Thus, current understanding of the impact on the partner of a chronic pain sufferer may be biased by the theories and definitions applied to the problem. It seems that an effective way to remediate these limitations would be to have spouses describe their experience of living with a chronic pain sufferer. Concept mapping is a method unrestricted by theoretical or constructual bias that enlarges the scope of inquiry and is consequently a relevant research alternative.

Concept mapping is a set of statistical methods that can be used for clustering qualitative data, or experiences into underlying themes as they are reported by participants rather than as they are defined by researchers (Daughtry & Kunkel, 1991; Trochim, 1989a). Kunkle (1991) stated that concept mapping methods can lead to a greater understanding of the perceptual themes underlying psychological disorders. He

further indicated that concept mapping can add objectivity to the study of qualitative types of data that have typically been analyzed using non-statistical approaches.

The concept mapping method involves three basic components: (a) generation of ideas, thoughts or experiences by participants about a specific question; (b) use of unstructured card-sort procedure, grouping of ideas or experiences that reflect common interrelationships; and (c) statistical analysis of card-sort results to determine underlying themes which are then depicted in map format (Trochim, 1989a). This method of qualitative data collection and analysis allows for the investigation of the experience of living with a CLBP sufferer from the participant's perspective.

Purpose of the Study

The need to more thoroughly understand the experience of female spouses of CLBP sufferers is warranted given the severity and breath of life disruption this population often experiences. The intent of the present study is to gain a relatively unconstrained description of the experience of female spouses of CLBP sufferers using concept mapping. This descriptive data will be analyzed to determine the presence of underlying themes. Finally, the incidence of experiences will be determined by surveying a larger group of female spouses of CLBP sufferers. Specifically, the study is designed to answer the following questions:

1) What are the reported experiences of spouses of CLBP sufferers?

2) What are the themes underlying experiences identified by spouses of CLBP sufferers?

3) What is the incidence of these experiences in a larger group of spouses of CLBP sufferers?"

The qualitative nature of concept mapping allows participants to describe the domain of their experience. Participants are further involved in the analysis of themes arising from their experiences. Therefore, results should more closely reflect the

experience, meaning and relevance of being a spouse of a CLBP sufferer, than prior research. A refined understanding of the experiences of spouses of CLBP patients could lead to the creation, delivery and evaluation of more effective programs specifically designed to treat negative consequences of chronic pain on the partner. Results may also guide effective integration of the partner in the treatment of the chronic pain patient. Direct practical application may exist for treatment team members of different disciplines working with CLBP sufferers at Workers' Compensation Board-Health Care and Rehabilitation Services, and similar programs. Concept maps can assist in the communication of important concepts clearly and easily. These maps can be particularly useful in educating various health care professionals. Finally, the results of this study may aid in the development of a scale based on the experiences of spouses of CLBP patients to assist in assessment, treatment planning, and program evaluation.

The participants of the study were female spouses of individuals who had sustained work-related injuries, had filed claims with the Workers' Compensation Board (WCB) of Alberta and, had been assessed or treated at the Rehabilitation Center in Edmonton, Alberta. The WCB is a statutory corporation entirely funded by employers with the mandate to carry out the Workers' Compensation Act. This Act states, in general, that workers waive the right to file a law suit against employers for work-related accidents. In return, the workers are entitled to no-fault insurance coverage that provides compensation and rehabilitation for work-related injuries. The WCB Rehabilitation Center is a division of the Board mandated to provide rehabilitation services to individuals and their families.

Spouses of CLBP patients attending the WCB Rehabilitation Center are an important group to study because of the magnitude of back problems among workers involved in WCB claims. In 1993, for example, 45% of the injured workers who attended the WCB Rehabilitation Center were suffering back-related injuries (Voaklander, 1994).

Limitations could arise using participants involved with the WCB. Processing of claims within a large bureaucratic organization often results in negative interactions and distrust of anything associated with WCB. It is possible that spouses of CLBP sufferers who had lingering complaints with WCB are more likely to volunteer to participate in this research.

Definition of Terms

Chronic Low Back Pain

Within this study the term chronic low back pain (CLBP) is defined as low back pain that has lasted for more than six months and whose origin is in the spine or surrounding tissue. The pain has persisted beyond the normal expected time of healing and has not responded to traditional medical intervention.

Spouse

In this study, the use of the term "spouse" refers to a cohabiting significant other. In some cases, the relationship between partner and pain sufferer may have ended during the course of the experience with CLBP.

In summary, CLBP is a significant personal and social problem in terms of economics, mental and physical health and family integrity. CLBP is a leading cause of physical limitation and disability, consumes inordinate health care and insurance claims dollars, and results in high rates of lost work days. CLBP sufferers experience difficult economic, psychosocial and relationship sequela. Adverse effects are not confined to CLBP sufferers but extend to family and spouses who experience disruption in several areas of their lives. CLBP spouses experience significant levels of depression/anxiety, decreased marital satisfaction and physical health problems. Spouses are not only impacted by chronic pain, but may have a significant role in the maintenance of pain, suffering and disability in their partners. The complex relationship between chronic pain its impact on spouses and the spouses' effect on the patient, suggests a need for

humanitarian treatment for spouses, as well as the need to acknowledge the partner as a potent player in the rehabilitation of CLBP sufferers. Effective treatment of spouses is required, particularly given the WCB mandate to treat patients and their families.

Current understanding of the impact on the partner of a chronic pain sufferer may be limited by the theories and definitions that have been applied the problem. Concept mapping is a method unrestricted by theoretical or constructual bias that enlarges the scope of inquiry and is consequently a relevant research alternative to existing theoretically-driven research.

This dissertation has the following format. Chapter 2 reviews literature concerning the impact of chronic pain on the spouse and family, the influence of the spouse on pain and the chronic pain sufferer, coping and chronic pain and treatments for spouses of chronic pain sufferers. As well, a general overview of concept mapping methodology is described. Chapter 3 provides a description of the methods used in the three phases of this research. In Chapter 4 results are presented and discussed. Finally, Chapter 5 presents a summary of the major findings, conclusions and implications for treatment.

CHAPTER 2: REVIEW OF LITERATURE

In this chapter literature will be reviewed to discuss the nature of chronic low back pain (CLBP) and enlarge on the social and personal costs of CLBP. In addition, the relationship of chronic pain to spouses of sufferers will be reviewed from two perspectives. The first describes the multifaceted impact of chronic pain on the partner of the sufferer. Second, the role of the partner in the maintenance of chronic pain is explored from a variety of theoretical perspectives. Finally, given that CLBP often represents a crisis for spouses and their families, a review of coping and treatment is presented.

Chronic Low Back Pain

Pain is defined by Chapman and Bonica (1985) as "an emotionally disabling sensory discomfort typically associated with tissue injury" (p. 4). This definition emphasizes the emotional and sensory nature of pain and that it may or may not be associated with tissue damage. To understand pain more fully, distinction needs to be made between acute and chronic pain.

Acute pain is primarily associated with active disease or traumatic injury. Pain secondary to injury results from increased activity of nociceptors and nociceptor afferents (Dwarakanath, 1991) and as such has a sensory etiology. This mechanism is normal and acts as a warning system to help prevent further injury. Typically, the pain resolves with healing of the injury.

When pain outlasts the course of injury, it loses its biological function and serves no useful purpose. This describes one type of chronic pain of particular importance to this research. Chapman and Bonica (1985) identified two other kinds of chronic pain: 1) that which accompanies a chronic medical condition; and 2) pain that develops and persists in the absence of an identifiable organic problem. In contrast to the adaptive

utility of acute pain, chronic pain is destructive and can lead to mental and physical disability (Dwarakanath, 1991).

Dwarakanath (1991) postulated several peripheral and central mechanisms for the development of chronic pain. One possible source of chronic pain is the continued discharge of afferents in the absence of stimulus or the presence of weak stimulus. This abnormal activity can be the result of sensitization of nociceptors by pain-producing substances at the time of the injury. Sensitized nociceptors may discharge from even slight pressure. Another possibility is the persistent stimulation of nociceptors that results from spontaneous activity as cut nerve terminals regenerate. A spontaneous activity similar to this is "cross talk" between bare axons demyelinated due to chronic irritation. Further, degeneration of small afferents in the dorsal horn and loss of neuropetidies and substance P. give rise to abnormal activity in both peripheral and spinal portions of the sensory system. Centrally, the thalamus coordinates the sensory and affective components of pain in the lateral and medial nuclei before relaying information to the cortex. Imbalance of thalamic function interferes with normal pain perception (Dwarakanath, 1991)

Wall and Melzack (1984) concluded that portions of the reticular formation inhibit transmission of pain impulses in the presence of normal sensory input. With reductions in sensory input, as in nerve lesions, inhibition is weakened and pain becomes persistent. Stress can likewise reduce reticular inhibition thus worsening pain, while rubbing, for instance, would increase stimulation, increase inhibition and decrease pain.

Another mechanism of particular interest has to do with the inhibitory effects of large nerve fibers on the transmission of impulses by small nerve fibers. In disorders involving pressure on nerves as in disc herniation there is a loss of large fiber activity. The loss of inhibitory large fiber activity allows unimpeded small fiber activity.

Psychological stress leads to increases in bradykinin and serotonin, which are pain sensitizing substances. Stress has been implicated with muscle spasm in a vicious cycle of pain continuance. Finally, operant mechanisms for the continuance of pain results from the continued reinforcement of pain behaviors first exhibited in an acute phase.

A move toward conceptualizing pain from a multidimensional perspective is easily understood given the physical, psychological and environmental nature of chronic pain as just described. In fact, pain is no longer viewed by informed individuals as a purely sensory phenomenon. Instead, it has been posited that an anatomical and physiological base for pain exists, but that the experience of pain involves a complex interaction of sensory, motivational and cognitive components (Melzack, 1973).

CLBP is increasingly viewed as a psychophysiological and psychosocial disorder, coupled with emotional maladjustment and cognitive-behavioral dysfunction. CLBP is experienced as a persistent unpleasant or noxious sensation of varying severity that may have a severely debilitating prognosis, both physically and psychologically (Turk & Flor, 1984).

Social Costs of CLBP

CLBP is a severe health and economic problem that affects a large portion of the population. Among all disorders only the common cold occurs more frequently than low back pain. Turk and Flor (1984) reported that 80% of adults have at least one episode of severe low back pain. Steinberg (1982) noted that pain is most often short-lived and, in fact, 90% of the cases remit within two months, however, relapse rates are high. Approximately 5% of patients have symptoms which persist longer than three months. In the U. S., low back impairments are the most frequent chronic conditions causing limitations of activities among individuals under 45 years of age (Girolamo, 1991) and the third leading cause of physical limitation and disability (United States Vital and Health Statistics, 1974).

It is estimated that more than 15% of all industrial injuries and more than 20% of all compensation payments in any given year are low back related (Sternback, Wolf & Murphy, 1973). Bonica (cited in Girolamo, 1991) reported that low back pain injuries account for more than 250 million lost work days a year and that the direct and indirect cost of low back pain approaches $24 billion per year in the U.S. Webster and Snook (1990) estimated from 1986 private insurance data that the total compensable cost of all low back pain in the U.S. was $11 billion and further stated that 25% of all cases accounted for 90% of the cost.

In 1988, according to The Back Association of Canada, 9 million work days were lost as a result of back pain, with the direct health cost at $2 billion. In a prevalence study of all adult residents of Edmonton, 44.3% reported chronic pain with backs (20.6%) being the most common site (Birse, 1994). In 1995, 16, 916 back claims were reported to the Workers' Compensation Board of Alberta. These claims resulted in costs of $75,783,292 and 377,707 compensation days (personal communication, Macleod, 1996).

Impact on Chronic Pain Sufferer

In addition to the tremendous societal burden, there is an enormous emotional cost to individuals and family members (Brockopp & Brockopp, 1990; Turk, Flor & Rudy, 1987). Many individuals experienced persistent pain and functional disability, which is in excess of what would be expected on the basis of the identified, underlying pathology (Carron, 1985). Strong (1985) noted that as a result these individuals perceive themselves as passive victims of their own circumstances who have no mastery over their fate or destiny. Many individuals stop working, eliminate potentially satisfying physical and social activities, and withdraw from friends and family (Subramanian, 1991). Turk and Holzman (1986) stated that the most common concomitants of CLBP are dependency, intrinsic anger, guilt, fear, anxiety, hopelessness, and depression. These

psychological disorders tend to be intensified by repeated failures in obtaining relief (Turk & Flor, 1984).

Literature on the impact of pain on the patient is large but not of particular relevance to this study on the impact on spouses. However, a study by Knish (1994), a precursor to the current study, used similar methodology and population but focused on the patient, not the partner. Eighty-three statements representing the functional, dysfunctional and neutral beliefs of interviewed chronic pain sufferers produced a concept map consisting of seven themes: denial/regret, self-defeating/passive, medication/pain focus, cautious realism, accepting limitations, adaptive coping and responsibility for rehabilitation. While the majority of beliefs for this group were adaptive, some beliefs could be problematic. For instance, back pain sufferers seem to struggle with denial and accepting the consequences of low back pain. Also, some CLBP patients indicated a need to stop relying on pain-related drugs, however, the majority believed that pain medication was the only way to reduce pain. The beliefs of a large number of respondents reflected difficulty with social interactions and that could lead to social isolation. Finally, many beliefs were endorsed which reflected lack of understanding of diagnosis and dynamics of their injures, especially functional limitation, which may contribute to ineffective coping.

Impact on Spouse

It was recognized (Strauss, 1975) that chronic illness not only affects the patient but can impact family life as a whole. Management of chronic illness typically involves the family to a greater degree than do acute conditions (Gerson & Strauss, 1975). As Litman (1974) suggested, "the family constitutes, perhaps the most important social context within which illness occurs and is resolved" (p. 495). In fact, it is generally acknowledged that health professionals are less important than family as caregivers for chronically-ill individuals (Strauss, 1975), and families maintain the primary

responsibility for care of chronically-ill and disabled family members (Stuifberger, 1987). In addition to the demands of caring for the chronically ill, and dealing with the patient's psychological distress and physical limitations, the family is often faced with the need to meet financial challenges, adjust to changes in roles, and accept greater responsibility.

It is generally acknowledged that chronic pain in an adult family member can have serious effects of the functioning on the family and its individual members (Flor, Turk & Rudy, 1987; Payne & Norfleet, 1986; Roy, 1982; Turk, Flor & Rudy, 1987). The deleterious effect of chronic pain on spouses, in particular is reviewed by Flor, Turk, and Scholz (1987). Spouses are adversely impacted in a number of ways by chronic pain in a family member. In their 1987 review, Flor, Turk and Scholz concluded that spouses most frequently experience dysphoric mood, marital dissatisfaction, and physical health problems.

Emotional Distress

One of the earliest studies to directly examine psychological distress in spouses of chronic pain sufferers (Shanfield, Heinman, Cope & Jones, 1979) found that patient spouses scored higher than nonpatient on the Symptom Checklist-90 (SCL-90) global symptom index and on many of the subscales as well.

More recent research corroborates that a high incidence of emotional distress is experienced by spouses of chronic pain sufferers (Ahern & Follick, 1985; Flor, Turk & Scholz, 1987; Saarijarvi, Hyyppa, Lehtinen & Alanen, 1990; Taylor, Lorentzen & Blank, 1990). Depression is the most common emotional complaint among spouses who frequently report significant comorbid levels of anxiety (Ahern & Follick, 1985). Almost one-quarter of spouses showed important levels of depressed mood (Flor, Turk & Scholz, 1987). In addition, 28% of spouses reported significantly depressed mood in a study by Schwartz, Slater, Birchler and Atkinson (1991). In general, depressive symptomotology is reported in the range of 20-50% among chronic pain spouses (Ahern & Follick, 1985;

Flor, Turk & Scholz, 1987; Kerns & Turk, 1984; Rowat & Knafl, 1985;). These figures are higher than the 16-19% of females in a community-control sample who reported depressive symptomotology (Comstock & Helsnig, 1976). Unlike other researchers, Schwartz, Slater, et al. (1991) reported higher levels of depression in the spouse than in the patient (Ahern, Adams & Follick, 1985; Flor, Turk & Scholz, 1987). They also found that the most frequently experienced depressive symptoms as measured by the Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erlbaugh, 1961) were, in descending order: fatigue, sleep disturbances, irritability, decreased efficiency, and decreased libido.

Taylor, Lorentzen and Blank (1990) assessed distress among chronic pain sufferers and their spouses by examining 61 couples (both male and female spouses) who reported to a pain management program. They used the SCL-90 with the intention of identifying specific patterns of symptomotology to which interventions may be directed. As expected, they found elevated levels of psychological distress among chronic pain sufferers and their spouses. In fact, spouses and chronic pain sufferers showed similar profile patterns with chronic pain sufferers consistently scoring higher, especially in somatization, hostility, and psychoticism. Spouses scored highest on somatization, depression and anxiety with spouses reporting the same level of depression as chronic pain sufferers. For this study, higher cognitive than somatic anxiety was indicated. Where as other researchers found higher somatic and lower cognitive levels of anxiety and depression in one sample (Buckelew, Burk & Brownlee-Duffeck, 1988) and higher levels of cognitive than somatic in another (Buckelew, DeGood & Schwartz, 1986).

Schwartz, Slater et al. (1991) examined five dimensions proposed in the literature that contribute to the development and maintenance of emotional distress in spouses: 1) patient's pain experience—pain intensity, impairment levels, and duration of pain, 2) patient's emotional distress —depression and anger (Ahern, Adams and Follick, 1985), 3) marital relationship, 4) the spouse's cognitive style, and 5) and the spouse's external

resources —social supports, economic resources, and patient employment status. This study of 29 male CLBP patients found three significant predictors of spouse's depressed mood: 1) patient's average pain, 2) patient's reported levels of anger and hostility, and 3) spouse's level of marital satisfaction. Results suggested that spouse's dysphoric mood may not only be in response to the general health status and psychological well-being of the patient, but anger and hostility in the patient may independently result in the spouse's dysphoric mood. In general, patients with higher levels of pain and/or anger had spouses who were more emotionally distressed. This female-based research points to a relationship between spouse's depressed mood, her satisfaction with the marriage and the patient's level of anger which may be explained by an approach-avoidance conflict paradigm (Schwartz, Slater et al., 1991). where spouses are simultaneously drawn toward their suffering husbands and pushed away by their anger and hostility. Spouses who have husbands in high levels of pain and anger may begin to feel helpless and depressed. Perception of lack of control over the patient's behavior and thus their own lives may play a part in feelings of depression and distress.

The relationship between depression and marital satisfaction was also described by Romano, Turner and Clancy (1989) in their research which explored the role of patient and spouse gender on the spouse's adjustment for CLBP couples. They found that the spouses of male patients reported lower marital satisfaction than the patients. Lower spouse marital satisfaction was associated with greater patient depression. Greater spouse depression was associated with greater depression and lower marital satisfaction in patients. When the patient was female, the spouse reported less depression than the patient. Female spouses were equally as emotionally distressed but were less satisfied with their marriages than their patient/husbands. The opposite was true of female patient/couples. Male spouses were less depressed than their patient/wives, but no less satisfied with their marriages. Romano, Turner and Clancy (1989) proposed that these gender differences may be attributed to greater sensitivity to nonverbal behavior by

females, the greater social inappropriateness of male depression and that work status of male patients may have a greater impact than for female patients.

Flor, Turk and Scholz (1987) found that spouses' experienced dysphoric mood when they perceived a lack of life control, were dissatisfied with their marriages, or when patients appraised the pain experience negatively. Spouses' mood was unrelated to patients' pain, mood or marital satisfaction, but was influenced by how patients reported they coped with the situation.

A multidimensional assessment of chronic pain spouses (Subramanian, 1991) examined extent and severity of psychosocial adjustment and the relationship of social support to the level of adjustment. In general, she found that this mixed group of male and female spouses were adversely impacted in multiple areas of their lives and that high levels of perceived partner support were related to better psychosocial adjustment. Specifically, this study suggested that impact is felt beyond personal and psychological areas and includes disruption of the social environment (48%), domestic environment (36%), health orientation (36%), extended family (19%) and vocational environment (16%). Her finding supported the notion that social support as a moderator of stress was important to the emotional well-being of individuals (Ell, 1984). Social support for spouses was largely obtained from friends, spouses and immediate family, and the quality of this support was moderately high. The most effective support was obtained from social workers, psychiatrists and psychologists but was accessed infrequently. Both quality and quantity of support from extended family was low. Subramanian (1991) identified risk factors for spouse adjustment as follows: female spouse, younger spouse, couple married for a shorter length of time, spouses reporting more marital dissatisfaction and less social support from their partners, spouses with social support from extended family and friends that was only moderately helpful, patients had a shorter history of chronic pain, patients with higher psychosocial dysfunction, especially in the area of

social interaction. It is generally thought that the greatest emphasis with couples would be most needed in the crisis stages of attempting to cope with the chronic pain.

Marital Consequences

Several researchers noted the presence of marital problems in chronic pain populations (Feinauer & Steele, 1992; Flor, Turk & Scholz., 1987; Kerns & Turk, 1984; Roy, 1985a, 1985b; Roy & Thomas, 1989). Ahern, Adams and Follick (1985) found that 35% of spouses rated their marriages as maladjusted and about 40% reported significant dissatisfaction with specific areas of marital functioning. Subramanian (1991) found that one-third of all spouses indicated marital disturbance. Kerns and Turk (1984) studied 30 male chronic pain patients and their spouses and found that 50% of patients and spouses reported significant depression and marital dissatisfaction. Coates and Ferroni (1991) interviewed 50 men with lumbar spinal injury who were recipients of workers' compensation benefits, along with their spouses, to ascertain effects on marital harmony and sexual functioning. All subjects reported disruption of sexual activity and increased marital disharmony as a result of back pain. It seems that these effects are stronger for chronic pain, especially CLBP, compared to other chronic conditions. For instance, compared to spouses of diabetics, chronic pain spouses experienced considerable change in marital and sexual satisfaction (Flor, Turk & Scholtz, 1987). Further, while most functioned fairly well, some marriages were severely disturbed.

Much research has sought to determine the nature or source of marital dysfunction in chronic pain couples. Marital dissatisfaction, disruption of roles and communication patterns, and sexual dysfunction occur in chronic pain relationships (Roy, 1989a). Marital disturbance was attributed to sexual dysfunction, communication problems, and changes in family activities (Subramanian, 1991). Maruta, Osborne, Swanson and Hallwig (1981) reported that 65% of spouses of chronic pain patients experience a negative change in marital satisfaction and 84% report a significant reduction in sexual

activity. Payne and Norfleet (1986) stated that 91% of couples report sexual problems. Subramanian (1991) suggested that a high level of marital disruption is expected for this population and that divorce is discussed most frequently when spouses are most pessimistic about their partner's recovery and return to work. In fact, of the 96 patients who attended her pain program in a year, 75% did not have spouses. Roy (1985a), on the other hand, indicated that marital breakdown in this population is low.

Bailis, Kulich and Wright (1984) found reports of depression among spouses was greatest for spouses who concurrently reported marital communication difficulties. Gender differences also were noted as spouses of male patients reported greater communication difficulties compared to spouses of female pain patients. Spouses have difficulty expressing anger with patients. Patients suffer losses of self-esteem and feel they have lost the right communicate both positive and negative feelings (Roy, 1985a).

Roy (1985a) examined the common problems that arise in marriages affected by the problem of chronic benign pain. In his work with chronic headache sufferers he found that marital difficulties were pervasive and profound. Aspects of the couples' lives that suffered included dramatic role changes, communication pattern dysfunction, sexual difficulties and the exchange of hostility and anger for affection and intimacy. Roy (1988) used the McMaster Model of Family Functioning and found problems in marital functioning in the following dimensions: 1) problem solving, 2) communication, 3) roles, 4) affective responsiveness, 5) affective involvement, and 6) behavior control.

A loss of partnership and the repetitive pattern of family functioning are often casualties when one of the partners become ill (Roy, 1985a). Spouses may either adopt a highly protective attitude and assume almost all of the patient's roles or patients may use pain to avoid unpleasant functions and force the spouse to fulfill those roles. In any event, significant role reversal appears common in chronic pain marriages. Another commonly observed behavior among male patients is the deliberate undermining of the

spouses' attempts to assume more responsibility and unwillingness to cooperate with tasks. These men may use pain to dominate their spouse and protect their concept of self. Overall, chronic pain in male patients frequently places wives in an untenable position, severely disturbing couples' patterns of role performance. Pain may be used as a socially acceptable excuse to end a difficult premorbid marriage.

Roy (1985a) reported that sexual incompatibility is the most common experience cited by pain patients and their spouses. Diminished sexual functioning may result in loss of patient's self-esteem and the spouse may experience a further sense of distancing and rejection as a result of sexual problems.

In a 1989 study, Roy and Thomas sought to provide even greater clarity regarding which aspects of couple functioning were affected by chronic pain. Couples were evaluated on five dimensions of family adaptability and five dimensions of family cohesion. Patients, as well as spouses, provided powerful evidence of marital discord and were in agreement on virtually every aspect. These marital relationships were found to be far from ideal and were not functional. Family adaptability was the major victim in which roles, rules and leadership were seriously jeopardized. Roles discarded by patients were either not performed or were expected to be assumed by the spouse who thus became significantly burdened and psychopathological. One of the alarming findings was that necessary roles for the well-being of the family tend to fall prey to chronic pain. Family cohesion, on the other hand, seems not to be so significantly impacted. These couples function on the borderline between being connected and separated, suggesting that the emotional bonding is loose. While patients had a sense of separation, spouses were more firmly connected and acted in ways that maintained family cohesion.

The two factors that emerged from the research of Coates and Ferroni (1991) as primary causes of marital disharmony were the inability of the patient to assume his "male role" and constant pain and its interference in sexual activity. All couples believed

their sexual relationship had suffered considerably as a direct result of the back injury. Thirty-six percent claimed sexual relations had ceased completely. All of the participants attributed these changes to extreme pain experienced when attempting intercourse. The 66% who continued sexual activity, indicated diminished pleasure, approached sex with fear of exacerbation of pain, or, for male patients, engaged in sexual intercourse out of a sense of duty. All subjects who continued sexual activity experienced pain during intercourse. Almost half of these complained that pain may persist up to 36 hours postcoitus, 53% experienced pain in the shaft of the penis, and 31% experienced testicular pain. Occasionally, premature cessation of sexual activity occurred as a result of these pains. Pain also accounted for erectile difficulty in 50% of subjects. Premature or retarded ejaculation difficulties were also attributed to pain.

All subjects reported that they used the male-dominant prone/supine position prior to injury. Only 16% had experimented with alternative positions in an attempt to relieve pain, which it seemed was because of rigid views of what is sexually appropriate. Coital orgasms were reduced from an average of 12.04 to 3.38 per month postinjury. This inability to engage in comfortable sexual activity was claimed to be a significant factor in reduced levels of self-esteem. Other factors were inability to continue as "breadwinner," perform household chores, or participate with father/child activities. Low self-esteem was exacerbated by alleged harassment from insurance companies, in-laws and the constant pain. Spouse and children reported that subjects constantly complained of pain and inability to perform physical tasks. Family relationships were strained and negative verbal interaction was common.

Other researchers investigated factors which might mitigate levels of marital dissatisfaction. Kerns and Turk (1984) studied 30 male chronic pain patients and their spouses and found that 50% of patients and spouses reported significant depression and marital dissatisfaction. They also found that high levels of patient depression accounted

for low marital satisfaction and perceived supportiveness. Spouse's adjustment was lower when they perceived less helpful social support from their partners.

High pain levels may be associated with impaired sexual functioning but not necessarily marital dissatisfaction. Spouses marital satisfaction is not affected by chronic pain per se, but rather is related to the overall quality of the marital relationships and the emotional status of the spouse (Flor, Turk & Scholz, 1987).

Likewise Block and Boyer (1984) found that spouse's cognitive interpretation of the patient's chronic pain was closely associated with the spouse's emotional adjustment and marital satisfaction. Positive emotional status in spouses was associated with optimism, perception that the patient had a positive attitude and few psychological problems, and the perception that the patient was severely disabled.

While most studies indicated marital maladjustment in response to chronic pain, Feinauer and Steele (1992) found that marital adjustment is not necessarily diminished in couples when a spouse suffers from chronic pain. Spouses in this study did not appear to have highly-distressed marriages, nor did the level of perceived pain and the presence of somatization account for level of adjustment in marriage. The authors discussed characteristics and mitigating factors that may account for these results. Spouse support was one such mitigating factor. A caretaking relationship was evident in 90% of this group. It seemed that both partners became adjusted to the clearly defined roles of patient and caregiver. Caregivers may have received some self-satisfaction and significance from helping the patient feel adjusted in the marriage. Patients may express appropriate empathy for the impact of pain on their spouse. The authors suggested that the high level of marital happiness indicated that it may be possible for couples to accept sexual limitations imposed upon them and adapt their relationship accordingly. This is especially true when limitations are externally imposed (Stahman & Hiebert, 1988). Feinauer and Steele(1992) found that reduced levels of distress was related to: 1) flexible

periods of the marriage life cycle, i.e., early in the relationship and later in the relationship, 2) perception that the chronic pain condition was nonthreatening to their lifestyle, 3) the belief that they have the problem within their control, 4) acceptance of the problem, or 5) attribution of positive meaning. Spouses perceived the pain problem as a problem to which the whole family can adapt and may be accounted for by the cultural values of family unity and extended family support. A final mitigating factor was religion, with 79% reporting that religion played an important role in their lives, and that maintaining the marital relationship was placed at high value. Beliefs regarding maintaining faith and hope through difficult times may have positively affected this population. Congruence of values, beliefs and feelings between spouse, patients and their environment may account for more marital satisfaction and adjustment.

While marital adjustment may be good for the spouse, it may have mixed effects for the patient. Flor, Turk and Scholz (1987) found that patients with better marital adjustment reported higher overall pain levels and had more solicitous and maritally satisfied spouses. Spouses' marital adjustment was positively associated with patients marital satisfaction and spouses' own mood.

Likewise, Block and Boyer (1984) found that while the spouse with a good marriage may feel better in general, such a spouse is likely to view the patient as having severe functional restrictions and is likely to avoid attributing patient difficulties to psychological or attitudinal factors. Happily married spouses can be expected to discourage activity and reinforce pain behaviors that would maximize pain and hinder rehabilitation. In other words, it appears that the pattern of adjustment which is most beneficial for the spouse has negative consequences for the patient. Block (1981) also indicated that the greater the marital satisfaction reported by spouses, the greater the risk of development of emotional, physical, and social illness.

A gender difference in marital satisfaction is reported in several studies (Flor, Kerns & Turk, 1987; Flor Turk & Rudy, 1989; Hafstrom & Schram, 1984; Kerns & Turk, 1984) in which husband's satisfaction with marital interaction was not significantly reduced by their wife's chronic pain while the reverse was true when husbands suffered from chronic pain.

Physical Consequences

Spouses may respond physically to chronic pain in their partners. In a study by Block (1981) spouses showed significant increases in skin conductance and heart rate when viewing videotapes of their partner patients in pain. Block (1981) and Block and Boyer (1984) suggested that such heightened arousal may eventually lead to physical symptoms in the spouse. This hypothesis is confirmed in a study by Rowat and Knafl (1985) where 23% of spouses reported significant physical health problems which they attributed directly to chronic pain in their spouse. An increase in pain symptoms in the spouse is reported by Mohamed, Weisz and Waring (1978) and Flor, Turk and Scholz. (1987). A remarkable finding by Mohamed et al. (1978) was that chronic pain patients and their spouses shared pain complaints, pain frequently emanating from the same part of the body. On the other hand, Flor, Turk and Scholz (1987) found that spouses of chronic pain patients showed no more physical symptoms than spouses of diabetics. However, chronic pain spouses reported significantly more pain symptoms that were related to elevated levels of depressed mood. Violon and Giurgea (1984) reported that chronic pain sufferers had significantly more pain patients in their families (78%), compared to a group of patients of chronic disease but pain free (48%).

A physical response to chronic pain seems to be gender related as female spouses had significantly more muscoskeletal pain symptoms in the neck and shoulders than the male spouses (Saarijarvi, Hyyppa, Lehtinen & Alanen, 1990).

Rowat and Knafl

The frequently cited research of Rowat and Knafl (1985) will be thoroughly described because of its qualitative nature and similarity to this study. This will allow for a comprehensive comparison of results between the two studies. Rowat and Knafl (1985) examined the spouse's perspective of living with chronic pain. This study involved 40 spouses (mixed male and female) whose partners attended a multidisciplinary pain treatment center. The study design was primarily exploratory descriptive, therefore the major data gathering instrument was a semistructured interview. Open-ended questions explored the spouse's perception of the pain problem, how he/she defined and described the experience of living with pain and how each attempted to manage the problem of pain. The interview focused specifically on:

> 1) areas of individual and family life perceived to have been affected by the pain, 2) those aspects of the situation considered most stressful, 3) the spouse's assessment and understanding of the pain problem, 4) the means by which the spouse attempted to control the pain and its effect on his/her life, 5) the spouse's expectation regarding the future of the pain problem, 6) the spouse's prior experience with pain, and 7) the spouse's past and present experience with health professional regarding their mate's pain problem (p. 261).

The McGill Pain Questionnaire (MPQ) (Melzack, 1975) and the Beck Hopelessness Scale (HS) (Beck, Weissman, Lester & Trexler, 1974) were completed by the patient and spouse. Interview data were analyzed in a manner described by Bogdan and Taylor (1975) and were coded according to the interview categories listed. Additional categories and themes were added based on interview content. Finally, the relationship among factors was explored.

Spouses' descriptions of pain referred mainly to sensory qualities and, with equal frequency, dealt with the "restrictive and dictating" aspects of pain. Uncertainty about

cause and persistence of pain was a dominant theme. MPQ scores were similar for spouses and their mates with the patient rating their pain slightly higher than did spouses.

The impact of pain involved disturbances of emotional, physical and social health. A majority (69%) of the statements made by spouses regarding effects of pain experience on their health had to do with emotional impact. This was characterized by sadness, depression, fear, nervousness, and irritability. Twenty-three percent of the statements were physical in nature and dealt with disturbances of sleep and appetite, increased blood pressure, migraine headaches and gastro-intestinal distress. With regard to their relationship with the pain sufferer spouses noted feeling both binding and separating forces of chronic pain. Twenty-five percent of spouses reported feeling restricted. On the other hand, the experience of feeling alone and feeling separated by the experience were expressed.

The most frequently identified problem of living with chronic pain mentioned by spouses was the "sense of helplessness they experienced at being unable to effect any change in their mate's pain and uncertainty as to how to proceed" (p. 264). In terms of pain management, spouses requested assistance with three categories of information: 1) information to gain some understanding of chronic pain, 2) information as to how to cope with pain and assist in its management, and 3) information regarding ways of dealing with the stress effects on their own lives.

Two extreme groups emerged from the data based on level of distress: one that displayed high levels of distress and another whose members claimed to be affected little by pain. Ten of the 12 high-distress spouses were female who reported feeling physically, emotionally and socially stressed. In addition to the health effects noted earlier, high-distress spouses experienced a sense of isolation and loss of freedom. Many of these spouses reported changes in four of seven life dimensions investigated (i.e., relationships with children, friends, marital partner, and friends; division of labor;

decision making; and financial functioning). This group, both spouses and mates, typically used emotionally charged descriptors such as, "pure hell" or "trapped." Spouses who reported changes in four dimensions of their mate's life also fell within the high-stressed group. A majority of patients in this group were unemployed due to the pain problem. All but one of the high-distress spouses assumed a "protector advocate role" in relation to their partner. This role included protecting the patient from stress and taking on responsibilities of the patient. Another finding was that high-distressed spouses rated their patient-partners' pain more highly than did the patient themselves.

Low-distressed spouses were mixed by gender and, in contrast to the high-distressed group, denied any major disturbance of personal or family life as a result of chronic pain. These spouses described their experience with much less emotion and fewer negative descriptors. Some couples felt the experience brought them closer. The partners of low-distressed spouses were different than those of the high distress in that number of years in pain was almost half, and there was less than half the unemployment due to pain. The spouses in the low-distress group perceived their mate's pain to be much less than those in the high-distress group even though the patients rating of their own pain was similar for both high and low. Low-distress spouses produced lower scores than their corresponding patient-mates on the MPQ.

The high-distress spouses adopted a role of protector, the low-distress spouses reported avoidance and ignoring behaviors. The amount of care required by patients of their spouses did not distinguish this group. Another factor that distinguished high from low distress had to do with the knowledge of spouses of behaviors or circumstances which enhance or inhibit pain of the mate. The high-distress group had almost half of its patients with CLBP, while less than one-quarter of the low-stress group experienced low back pain.

A central theme that emerged was that of uncertainty, mainly of the nature of chronic pain itself. One of the outcomes of the uncertainly of the pain was that of an uncertain family life. It is suggested that the perception of living with daily unknowns and consequent inability to control one's life because of the uncertainties was a major factor in the distress of spouses. A second major outcome of the uncertain nature of pain was the uncertainty of management. Many spouses found that coping skills developed to meet previous and different crises were ineffectual to meet the demands of chronic pain. Rowat and Knafl (1985) proposed that "uncertainty precluded the development of appropriate management strategies and renders the spouse impotent" (p. 268). Finally, they concluded that "health professionals must extend their focus of attention beyond that of the pain patient to the family as a whole. Furthermore that the results of this study would argue for a reconceptualization of the pain patients' family from that of a 'villain' to one of 'victim' of the pain experience" (p. 269).

Coping with Chronic Pain

Coping refers to adaptation to difficult circumstances. Conditions that are drastic enough to defy familiar ways of behaving and may concurrently result in emotional discomfort call for coping. Coping requires the production of new behavior so that one can adapt to the change or problem and get relief from emotional consequences (White, 1985). Lazarus and Folkman (1984) defined coping specifically as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 178). These descriptions of coping share the basic understanding of coping as an attempt to manage excessive demands. Lazarus and Folkman (1984) specified cognitive as well as behavioral efforts to cope with internal as well as external demands.

Two broad categories of coping responses are proposed by Lazarus (1981). The first is problem-focused coping, which is the taking of focused action to eliminate the

problem or change a situation. Emotion-focused coping, on the other hand, attempts to modify emotional functioning in the face of the stressful situation. Most events require a balance of both types of coping with one or the other weighted more heavily, depending of the situation.

Three commonly used assessment devices for coping provide a catalogue of coping responses. The Problems of Everyday Living Scale (Pearlin & Schooler, 1978) organize 17 coping behaviors according to three functions: 1) attempts to modify the situation (e.g., self-reliance, advice seeking, negotiation), 2) attempts to control the meaning of the situation (e.g., selective ignoring, positive comparisons), and 3) attempts to manage the stress of the situation (e.g., controlled reflectiveness, passive forbearance).

The Health and Daily Living Form (Cronkite & Moos, 1984) presented a two-concept model for organizing coping data. Active-cognitive coping, active-behavioral coping and avoidance coping are included as methods of coping. The focus of coping included logical analysis, information seeking, problem solving, affective regulation and emotional discharge.

Folkman and Lazarus (1985) distinguished between problem-focused, emotion-focused and mixed problem-and emotional-focused coping in their Revised Ways of Coping Checklist. They included in emotion-focused coping; wishful thinking, distancing, emphasizing the positive, self-blame, tension reduction, and self-isolation. Seeking social support was considered mixed problem-and emotion-focused coping.

Considerable research has been devoted to determining effective coping in general. However, the relative adaptiveness of a particular coping response and the most effective methods of coping is influenced by the nature of the particular situation (Kaplan, Sallis & Patterson, 1993). Recently, a number of studies have attempted to identify the most effective ways of coping with specific stressors. However, relatively few of these studies have examined coping strategies among the chronically ill. One

study of cancer patients (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992) used the Ways of Coping Inventory (Folkman & Lazarus, 1988) to identify five coping strategies used by this group: 1) social support/direct problem solving, 2) distancing, 3) positive focus, 4) cognitive escape/avoidance, and 5) behavioral escape/avoidance. The ways that people cope with other chronic conditions like chronic pain may not be confined to, or include, any of these five strategies.

The Coping Strategies Questionnaire (CSQ) was developed by Rosensteil and Keefe (1983) to assess efforts made by chronic pain patients to control their pain The seven strategies in the instrument are: diverting attention, reinterpreting pain sensations, catastrophizing, ignoring sensations, praying or hoping, coping self-statements and increased behavioral activity. Research is needed to identify the particular coping strategies used by chronic pain sufferers and to then analyze which of these facilitate psychological adjustment and which contribute to poor adjustment.

The Chronic Pain Coping Inventory (CPCI) was developed by Jensen, Turner, Romano and Strom (1995) to measure coping strategies, both encouraged and discouraged, that are targets of multidisciplinary pain programs. It is viewed as complimentary to the CSQ which includes cognitive coping dimensions. The CPCI has three broad scales. Illness-Focused Coping includes guarding, resting, asking for assistance, opiod medication use, nonsteroidal medication use, and sedative-hypnotic medication use. Wellness-Focused Coping includes relaxation, task persistence, exercise/stretch, and coping self-statements. Another way of coping is to seek social support. The CPCI is unique as it has a significant-other version which provides greater objectivity regarding patient functioning and adjustment.

A series of studies may shed light on which coping strategies, in general, contributed to good or poor adjustment. Avoidant coping, for example, is associated with increased psychological distress in response to stress (Holohan & Moos, 1987). Felton,

Revenson, and Hinrichsen (1984) found that cognitive restructuring contributed to good emotional adjustment among chronically ill, while coping by fantasizing, expressing emotion or blaming oneself contributed to poor adjustment. Information-seeking and threat minimization were unrelated to adjustment. In rheumatoid arthritic patients, low helplessness has been associated with superior psychological and behavioral functioning and reduced symptom severity (Frenzel, McCaul, Glasgow & Schafer, 1988). These types of studies highlighted a variety of coping responses and suggested those which were more helpful for specific situations.

Studies specific to chronic pain patients suggest that positive self-statements, ignoring pain, and increasing activities are associated with better psychological functioning (Jensen & Karoly, 1991; Keefe & Williams, 1990). Improved physical functioning has been associated with diverting attention from pain, ignoring pain, and use of coping self-statements (Jensen & Karoly, 1991). Rest is allied with poor physical functioning (Jensen, Turner, Romano & Karoly, 1991).

Other studies suggest that the utility of a coping strategy for any given chronic disease may depend on the point in the course of the disease. Levine et al. (1988) found that high denial contributed to adjustment in intensive care but that after a year postdischarge high deniers showed poorer adjustment to disease. While the effectiveness of a coping response may be determined by the nature of the event and the point in the course of the event, it is generally concluded that active coping efforts are more consistently associated with better adjustment than avoidant strategies, as long as the event is amenable to active coping efforts (Taylor & Aspinwall, 1993).

Taylor and Aspinwall (1993) discussed issues related to measurement of successful coping. Traditionally treatment success was measured by length of survival or signs of presence or absence of disease. More recently quality of life has been acknowledged as an important indicator of coping and treatment success. Thus, objective

medical indicators give way to psychological, social and economic factors as measures of quality of life. Quality of life indicators for specific illnesses will help to determine which coping methods are used, and are effective and to identify the impact of treatments. Until very specific quality of life indicators are established for different chronically ill groups like chronic pain sufferers, reliance on traditional measures of coping will continue. This includes primarily biochemical functioning, return to prestress activities and reduction of psychological distress. In the case of chronic pain, substantial life change and failure to return to prestress activities may not always reflect unsuccessful coping.

Some research among the chronically ill indicated that many do not simply cope but that these events can bring about positive changes in their lives. In a study of cancer patients (Collins, Taylor & Skokan, 1990) over 90% of the respondents found at least some beneficial changes in their lives. They reported an increased ability to appreciate each day, that they were putting more effort into their lives, that they had developed a greater awareness of others' feelings, that they experienced increased sympathy and compassion for others and that they had become more self-assured as individuals.

Very little research has explored coping, pain, and family members. Those that exist have sought to evaluate the effect of family members' coping patterns on the pain sufferers' functioning. Cronkite and Moos (1984) showed that the spouse's coping patterns influenced the level of distress in the patient. Another study (Dunn-Geier, MacGrath, Rourke, Latter & D'Astous, 1986) found that the presence of an overprotective mother who discouraged activity could predict poor adolescent coping with pain. These studies have considered the coping of spouses and family members as it affects the well-being of the pain sufferer. What is lacking, it seems, is any investigation of coping among spouses and family members of CLBP sufferers as it relates to their own functioning.

Role of Spouse in the Maintenance of Chronic Pain

Solicitousness

An operant conceptualization of the role of the spouse and the family in the maintenance of chronic pain has been supported by a number of studies (Flor, Kerns & Turk, 1986; Flor, Turk & Rudy, 1989; Kermer, Seiber & Atkinson, 1985; Kerns, Haythornthwaite, Southwick & Giller, 1990; Lousberg, Schmidt & Groenman, 1992; Romano, Turner, Friedman et al., 1992; Turk, Flor & Rudy, 1987). The overall idea is that the solicitous spouse may unwittingly contribute to the patient's pain experience through selective and specific reinforcement of pain behaviors. On the other hand, the spouse who ignores or selectively ignores or punishes pain behaviors may, in fact, be functioning to decrease the frequency of pain behaviors and improve the patients' overall functioning.

Duration of the pain problem (Flor, Kerns & Turk, 1986) and pain intensity increases are related to spousal solicitude (Flor et al., 1986; Turk & Rudy, 1988). Self-reported pain severity is positively correlated with the frequency of pain contingent behavior from the spouse (Kerns, Haythornthwaite et al., 1990). When pain patients were observed by solicitous spouses, they reported high pain levels as compared to a neutral-observer condition (Block, Kerner & Gaylor, 1980), or compared to observation by relatively nonsolicitous spouses (Lousburg et al., 1992). Subjective pain intensity increases occur as a result of spousal reinforcement of overt expression of distress and suffering (Turk & Rudy, 1988). Interestingly, it seems that CLBP intensity is particularly vulnerable to the effects of spousal solicitousness compared to other chronic pain conditions: rheumatoid arthritis and sickle cell anemia (Anderson & Rehn, 1984).

An increase in pain behaviors is also a consequence of reinforcement (Turk & Rudy, 1988). As well, Romano, Turner, Friedman et al. (1992) found that solicitous behaviors of spouses were significantly more likely to precede and follow nonverbal pain

behaviors. Similarly, as predicted by operant conditioning theory, nonverbal pain behaviors were significantly less likely to follow spouse aggressive behaviors.

Activity levels in chronic pain patients are influenced by spousal solicitude. A treadmill test showed that in the presence of solicitous spouses, pain patients walked for a shorter duration than in the presence of relatively nonsolicitous spouses (Lousberg et al., 1992). Flor, Kerns and Turk (1986) found that spouse reinforcement explains almost one-third of patients' activity levels.

Remedial effects of the reversal of solicitude are also noted. Fordoyce et al. (1973) demonstrated an increase in physical activity and decrease of pain behaviors when attention was withdrawn from pain behaviors, and activity was followed by attention and praise. Flor, Kerns and Turk (1986) also found that when spouses ignored pain or responded negatively to it, patients were shown to be more active.

The degree to which spousal solicitude impacts the pain of patient is associated with levels of marital satisfaction. While patients with solicitous spouses had more pain they also were more satisfied with their marriages (Flor, Turk & Rudy, 1989). When relationships were satisfying , patterns of solicitous responding to pain corresponded to increases in pain severity (Kerns et al., 1990). These researchers showed, conversely, that patterns of responding to pain may have little relationship to reports of pain in the context of unsatisfying relationships.

Kerns, Haythornthwaite et al. (1990) described the interaction between marital satisfaction, operant behaviors and depression. They reported that in marriages with low satisfaction, high frequency punishing responses results in depression in pain patients while high frequency punishing responses within the context of marital satisfaction resulted in low levels of depression. They noted a decrease in pain and suffering when selective ignoring and punishing of expressions of pain occur within a context of high frequency positive communication by spouses.

Flor, Turk, and Rudy (1989) found that the magnitude of the relationship between reinforcement and pain is mediated by gender, marital status and marital satisfaction. Female spouses' marital satisfaction scores were lower than the male spouses'. Women seem to be more distraught about their husbands' chronic condition than men are about their wives'. Again, patients who rated their marital relationship as unhappy also showed lower associations between spouse responses and total pain impact scores. It is suggested that spouses may have less reinforcement power if the marital relationship is unsatisfactory. This may be because a maritally dissatisfied spouse may be less attentive and less aroused by their partner's pain behaviors and may thus respond in a less solicitous fashion. Overall, predictions were better when the patients' perceptions of significant others' reinforcement were used, compared to the significant others' self-reported responses.

In summary, when spouses reinforce expressions of pain, pain intensity and behavior increase, the duration of the pain problem is extended and activity levels are reduced. Conversely, when pain in the partner is ignored or responded to negatively, pain and pain behaviors decrease and activity levels increase. The perception of the patient regarding spouses' reinforcement (Flor, Kerns & Turk, 1986) is a better predictor of these phenomenon than spouses' self-reports. The strength of operant factor's deleterious effects on chronic pain patients is greatest in satisfying marriages. To reduce the effects of the interaction between marital satisfaction and solicitousness and depression, Kerns, Haythornthwaite et al. (1990) suggested selectively ignoring and punishing expressions of pain and reinforcing desired behaviors while remaining globally positive.

Collusion and Systems Theory Models of Pain Maintenance

Some researchers suggested chronic pain or illness complaints can serve an equilibrating function within a distressed relationship (Haley, 1963; Meissner, 1980; Minuchin, 1974; Mohamed, 1982; and Waring, 1977). It is believed by those holding

this view that focusing on patients' pain problem and encouraging chronic behavior reestablishes "sick-role homeostasis" and allows the spouse to deny any marital difficulty. Delvey and Hopkins (1982) characterized such relationships in terms of collusion or unconscious contracts or agreements between patient and spouse defining reciprocal behaviors or roles. These couples tend to characterize their marriages and each other in idealized terms and thereby obviate the relevance of couples' therapy. Swanson and Maruta (1980) described this dynamic as an "undesirable mutuality" and noted that it is associated with resistance to treatment, noncompliance and very poor prognosis. Thus, chronic pain and disability might serve as a solution to some problem within the relationship.

Beliefs

A review by DeGood and Shutty (1992) concluded that patients' beliefs about their pain play a prominent role in pain perception, function and response to treatment. Furthermore, patients who believed the treatment was applicable had much better outcomes (Schwartz, DeGood & Shutty, 1985; Shutty, DeGood & Tuttle, 1990).

Agreement among family members' conceptions of an illness has been related to successful treatment outcome (Swanson & Maruta, 1980). Family attitudes have been shown to be a major factor in patient compliance with recommended treatment regimes (Ferguson & Boyle, 1979; O'Brien, 1980).

The knowledge and beliefs of family caregivers about chronic pain patients are explored by Benjamin, Mawer and Lennon (1991). Most caregivers held inappropriate beliefs that counter known effective rehabilitation practices for chronic pain. They believed that pain resulted from a yet undiscovered physical cause, considered surgery, appeared to pursue a curative model of treatment, regarded their role as "protector-advocate," often initiated medical consultations, were uncertain about future treatment, encouraged rest, and discouraged patient self-reliance. These researchers also found that

caregivers had been given little useful information regarding the nature of chronic pain, its appropriate treatment and their own potential contribution.

Spouses are potently influential and when they hold inappropriate beliefs as is indicated by Benjamin et al. (1991), they may reinforce their partner's counterproductive beliefs, collaborate in patient dysfunctional rehabilitation efforts, and overall, contribute to unsuccessful treatment compliance and outcomes.

Treatment of the Chronic Pain Family

Brockopp and Brockopp (1990) suggested that much of the treatment of chronic pain that includes the family has the purpose of improving the pain sufferer's condition. In these cases family members are viewed as perpetuating or exacerbating the problem and are used as tools to help modify the patient's counterproductive behaviors and decrease pain. But as Jeans and Rowat (1984) indicated, the family may itself suffer as a result of having a member experience chronic pain. In this case the members of the family would become the patients. While the importance of including the pain sufferer's family in treatment has been substantiated (Flor, Turk & Rudy, 1987) empirical investigation has not provided clear direction for such intervention.

A series of studies conducted by Saarijarvi and various contemporaries (1990, 1991, 1992) investigated the effects of couple therapy in various aspects of the functioning of CLBP patients recruited from primary health care centers. In a controlled study of marital satisfaction, psychological distress and health attitudes, Saarijarvi (1991) found that couple therapy improved the quality of life of CLBP patients by enhancing marital communication and possibly reducing psychological distress in male patients. The couples received five monthly sessions of family systems oriented therapy. Marital adjustment decreased for the treatment group, but decreased even more for the control group. No significant differences were found for any of the measures in spouses.

In what was probably the first randomized controlled study from community health care centers, Saarijarvi, Rytokoski and Alanen (1991) investigated the effects of couple therapy on disability. The same couples were assessed at 6 months and one year posttreatment (Saarijarvi, Hyyppa, Lehtinen & Alanen, 1990). The authors' conclusion that couple therapy had no significant effects on disability is mitigated by the relative lack of marital dysfunction, prior treatment with the Swedish Back School and the brief duration from treatment to follow-up.

The long-term effect of couple therapy on psychological distress, marital satisfaction, health locus of control, pain and disability and clinical findings were assessed by Saarijarvi, Alanen, Rytokoski and Hyyppa (1992). Five years after family systems intervention patients were assessed on these measures. A significant reduction in psychological distress for the treatment group included depression, anxiety, hostility, and obsessive-compulsivity.

Moore and Chaney (1985) compared comprehensive cognitive-behavioral group therapy with and without spouse participation to waiting list controls for eight bi-weekly two-hour sessions. Pain patients improved in many conditions relative to controls, but a finding of relevance to this discussion is that spouse involvement did not produce any benefits to pain treatment even though operant formations of chronic pain maintenance were explained. Also of interest is that spouses commonly reported how helpful treatment was for them in helping them learn to cope with patient's pain and behavior and their emotional reactions to their spouse. These findings call to question the significance of operant chronic pain maintenance and highlight the need for future studies to assess changes in the spouses of pain patients. These conclusions, however, are mitigated by the relative passive involvement of the spouses in this treatment. Further, if marital status and marital satisfaction were considered as is suggested by Flor, Turk and Rudy (1989), the results may have been different. In any case, it is possible that for subgroups of pain patients, treatment based on operant models may be helpful.

Studies that assess treatment effectiveness for spouses of chronic pain sufferers are sometimes limited. An uncontrolled study (Langelier & Gallagher, 1989) of outpatient chronic pain patients and their spouses significantly reduced problems related to chronic pain in both the patient and the spouse. A cognitive family therapy study obtained favorable results with couples (Waring, 1982). Hudgens (1979) combined operant treatment and family therapy in 24 families with chronic pain members. She found that when the family was supportive the patient was more successful. It was not possible to measure the contribution of the spouse in this study.

Many pain researchers (Roy , 1989b; Turk, Flor & Rudy, 1987) have concluded that families should be included in treatment "because of the potential negative impact chronic pain can have . . . and the possible reciprocal effects on the patient" (Turk, Flor & Rudy, 1987, p. 39). Yet after an extensive review of family therapy and pain and illness literature , Flor, Turk and Rudy (1987) acknowledged that little was known about the advantages or disadvantages of including the family in the patient's treatment or what family involvement should look like. Research of the past nine years has done little to answer these questions, in fact, the meager amount of research that has been done has focused primarily on the wellness of the pain patient.

Although inclusion is generally called for it is thought that it may not always be necessary to intensely include the family in all cases (Flor, Turk & Rudy, 1987). Selection for intense family treatment may be based on categorization of patients according to the West Haven-Yale Multidimensional Pain Inventory (WHYMPI) (Kerns, Turk & Rudy, 1985). Data suggest that the category of patients, accounting for 30%, reporting inadequate social support were most likely to benefit from intense family involvement compared to globally dysfunctional patients and adaptive copers. Here again, the focus on the patient tends to ignore the treatment needs of the spouse and family.

A necessary step to determining suitability for inclusion of the family in chronic pain treatment and for the development of treatment plans is assessment of family functioning as described by Brockopp and Brockopp (1990). Assessing the degree that chronic pain disrupts the family's ability to meet its developmental tasks is one way to do this. The developmental tasks of most families as identified by Duvall (1971) are: physical maintenance—the provision of basic necessities such as food and shelter; resource allocation—the allocation of material good, and emotional attention; division of labor—assigning chores in order to manage the household; socializing family members—assisting family members to grow in a valued direction; the inclusion/release of family members—rearing children so that they are comfortable to leave at maturity; maintaining order—assigning sanctions in keeping with family norms; placing family members in the larger society—school, religious organizations; and maintaining motivation and morale—developing a sense of family togetherness. In the case of chronic pain, for instance, therapy may help the family reorganize to adjust to changes in physical maintenance, resource allocation, and maintaining motivation and morale.

Ahern and Follick's (1985) finding that emotional functioning of the spouse appears to have a bearing on the response of the patient to treatment, suggests a need to treat emotional distress of partners. Low spouse MMPI scale scores on Depression and Mania predicted more favorable treatment outcome for patients while higher Psychasthenia and Schizophrenia predicted favorable outcome.

Roy (1985b) suggested indicators for determining the suitability of marital partners for treatment. When patient and spouse are anxious to resume normal existence the following characteristics are evident: 1) a willingness to change, 2) willingness to accept responsibility for pain behaviors, 3) patient becomes functional in some areas of daily living, 4) willingness to accept psychological or nonmedical explanation for pain behaviors, 5) willingness to enter into psychological therapy, and 6) positive premorbid marital history. On the other hand, unsuitability for treatment may be indicated if there is

evidence of: 1) entrenchment of the sick role, 2) medicalization of cause of pain, 3) commitment to finding a medical cure, 4) rejection of psychological approaches and, 5) premorbid history of conflict and difficulties in marriage.

CLBP has severe consequences for society, patients, and spouses. Emotional distress, marital disruption and physical illness are described in the literature as prominent consequences for spouses of CLBP sufferers. However, that which is known about the impact of CLBP on spouses is limited by theoretical and constructual biases inherent in prior research. What is needed is research that allows for unrestricted description of the experience of living with a CLBP sufferer, at the same time, provides for objective analysis of that experience.

Concept Mapping

Concept mapping is a relatively new methodological approach that is particularly appropriate for applications where researchers are seeking to clarify the domain, constituent elements, and underlying structure of a phenomenon as experienced within the population of interest (Kunkle, 1991; Trochim, 1989b). The phenomenon of interest in this study is the experience of female spouses of CLBP sufferers.

Early application of concept mapping was for program planning and evaluation involving large groups and committees (Trochim, 1989a). It has also been applied to the field of psychology (Fitzgerald & Hubert, 1987). Kunkle (1991) used concept mapping in his study of psychological disorders to elucidate themes underlying these pathologies. More recently, the dysfunctional beliefs of battered women (Deby, 1993), the problems of remarried families (Phillips, 1993) and staff's view of supported employment programs for individuals with severe mental illness (Trochim, Cook & Setze, 1994) have all been explored using concept mapping. Of particular interest, given the topic of this study, is the work of Knish (1994) in his concept mapping of the beliefs of CLBP sufferers. He reported that concept mapping (Knish, 1994) is a particularly useful tool for elucidating a

psychological phenomenon, determining themes which may underlie a phenomenon and presenting themes in an effective visual format. Concept mapping data has become an important part of Knish's individual and group treatment of CLBP sufferers with whom he works as team psychologist at WCB (personal communication, 1995). Concept mapping is likely to be equally as well suited to describing the experience of female spouses of CLBP sufferers and determining the underlying themes of their experience.

Trochim (1989b) has outlined three basic components in concept mapping's structured conceptualization process: 1) a specified group of subjects generate ideas, thought, or experiences about a specific research question, 2) common interrelationships between ideas or experiences are grouped together according to a common theme through an unstructured card-sort procedure, and 3) statistical analysis of the card-sort results are conducted to determine underlying themes and the results are depicted in a map format.

Part of the concept mapping process is the categorization of ideas along thematic lines using statistical methods. Concept mapping has the advantage of adding objectivity to the study of qualitative types of data which have typically been analyzed by researchers using subjective judgment without the use of statistical methodology (Kunkel, 1991). Rosenberg and Kim (1975) indicated that "the identification of underlying dimensions can take place from the structures obtained by scaling and clustering, leaving the respondent's judgment uncontaminated by an investigator's preconceptions" (p. 490). It allows for the clustering of qualitative data, or experiences, into underlying themes as they are reported by participants, rather than as they are defined by researchers (Daughtry & Kunkel, 1991; Trochim, 1989a). A participant's experience and perspective are reflected for a given phenomenon.

A related advantage is found in the fact that data are grouped by many sorters which reduces the potential for bias and subjectivity compared to the thematic analysis of qualitative data by individual investigators.

Finally, the concept map has practical utility. It statistically organizes principles implicit in the participants' sorting and presents this information in a highly usable visual map (Daughtry & Kunkel, 1993). The utility of a graphical representation of a data analysis is emphasized by Trochim (1989b) when he states that the concept map "at a glance shows all of the major ideas and their interrelationships" (p. 16).

Kunkle (1991) concluded that unlike the nonstatistical analysis of qualitative data, concept mapping, with its statistical rigor, adds objectivity. The consequent validity of the description and interpretation of the experience of participants makes this methodology particularly valuable for the determination of themes that express the experience of living with a chronic pain sufferer.

Six steps are involved in the development and use of concept maps, namely: 1) preparation, 2) generation of statements, 3) structuring of statements, 4) representation of statements as a concept map, 5) interpretation of the map and, 6) utilization of the map.

Preparation

Selecting participants and a specific focus for research are the preparatory steps to the concept mapping process (Trochim, 1989b). Concept maps have been developed using a wide variety of relevant people, often using small homogeneous groups and even acquiring participants through random sampling methods. Groups are most commonly between 10 to 20 people, but may be as large as 80 or more (Trochim, 1989b). After establishment of the participant group, a clear focus of study is defined. Trochim (1989b) suggested that effective questions are clearly and simply worded and have a single focus.

Generation of Statements

Once the preparatory steps have been completed, concept mapping begins with the generation of a set of statements that reflect the participants perception about the research question. The goal is to generate a set of statements that represent the conceptual domain for the topic of study. The statements themselves can be generated

through a brainstorming process (Osborn, 1948) in which the participants state in sentence form all their perceptions about the research question (Trochim, 1989b).

The statements from all participants are collected, combined and redundancies are deleted. The intent is to distill from participants' written responses an inclusive subset of "meaning units" or items that capture the essence of the phenomena while retaining participants' language. The remaining statements are reduced to a maximum of 100 statements since more than 100 statements make the sorting process very difficult (Trochim, 1989b).

Structuring of Statements

A card-sorting procedure is conducted on the edited list of statements in order to identify interrelationship between statements. For the sorting task, each statement is printed on a mailing label format. A group of sorting participants is then chosen which may be, but are not restricted to, the same individuals who participated in the initial statement generation. After a complete set of statements is given to each sorter, each is asked to sort the statements into groups having a common idea of theme in a way that made sense to them. There are no restrictions on either the size or number of groups (Kidder, 1981; Trochim, 1989b). However, participants are to place each statement in only one pile, not to place all the statements in a single pile and not to place all statements in their own pile (Trochim, 1989b). Weller and Romney (1988) pointed out that one strength of unstructured sorting is its ability to accommodate a large number of items. A further advantage of the sorting procedure is that it is easily understandable by participants and that it takes little time to accomplish.

The grouped statements are then collected from the sorting participants. Data are put in the computer preparatory to a series of statistical procedures. The statistical technique of multidimensional scaling (MDS) is performed on the card-sort data to suggest statistically and visually the organizational principles implicit in the participants'

sorting (Davison, Richard & Rounds, 1986). Cluster analysis is then used to identify conceptually similar groups of sorted items (Borgen & Barnett, 1987). These analyses identify the common categories that emerge when the item groupings determined by individual sorters are considered in combination (Miller, Wiley & Wolfe, 1986; Wiley, 1967).

Representation of Statements

The statistical procedures involved in the representation of statements involve several steps. First, the results of the sort for each person are put into a square table or binary similarity matrix in which each of the values of the matrix are either zero or one. Second, the individual sort matrices are added together to obtain a combined group similarity matrix which has as many rows and columns as there are statements. This final similarity matrix is considered the relational structure of the conceptual domain because it provides information about how the participants grouped the statements (Trochim, 1989b).

Multidimensional scaling techniques are then applied to the similarity matrix using a nonmetric two-dimensional solution. There are three steps involved in the representation of the conceptual domain. First, an analysis is conducted that locates each statement as a separate point on a map (point map). Statements which are closer to each other on this map were likely to have been sorted together more frequently and thus are thought to be more similar conceptually. Second, the statements on this map are grouped or partitioned into clusters (cluster map) that represent higher order conceptual groupings of the original set of statements. Finally, maps are constructed which overlay the average rating either by point (point rating map) or by cluster (cluster rating map) (Trochim, 1989b).

Interpretation of Maps

The final step involved the visual inspection of each group of statements, or themes, derived from the statistical analysis. Each theme grouping is given a title which describes the contents of that group. This identification process can be completed by the original sorters or by the researcher(s) (Trochim, 1989b). After initial articulation of the themes, the ideas are qualitatively classified into hierarchical concepts. Novak and Gowin (1984) found that the development of a hierarchy has been useful with some data sets.

A concept map is a visual representation of the concepts developed in the analysis and interrelationships between theme groupings. Clusters of statements that are closer together on the cluster map should be more similar conceptually than clusters which are further apart. This final result provides a concise and simplified summary of the conceptualization (Trochim, 1989b).

Utilization of Maps

Trochim (1989b) contended that the results of the concept mapping process can be used to plan or evaluate treatment programs. They can also provide an understanding of the topic of study from the participants' perspective. In addition, he states that each category or grouping can be viewed as a measurement construct which can be used to provide direction for future research. Lastly, the pictorial format of the actual map is likely to help individuals understand and retain the essential ideas that are presented. As a result, the concept maps can be used effectively for communication and educational purposes. Knish (personal communication, 1995) has found concept maps to be effective tools in the group or individual psychotherapy setting.

Summary

CLBP is a significant social problem in terms of economics and family integrity. It is also a difficult personal issue that can have severe negative consequences for the

sufferer. Adverse effects of chronic pain extend beyond the patient to the family and spouses who experience significant disruption in several areas of their lives, notably but not confined to, emotional, marital and physical health.

The emotional, marital, and physical consequences of living with a chronic pain patient seem to demand increased coping efforts, especially for female spouses. Research to date has investigated coping and the chronic pain patient, or has looked at the effects of the coping of the spouse on the patient. What is lacking is research on coping as it relates to the functioning of the spouse.

Successful treatment of chronic pain spouses will likely be achieved in programs based on a thorough understanding of the impact on living with a chronic pain sufferer. With the exception of Rowat and Knafl (1985) who combined semistructured interview with two self-report measures, research assessing the impact of chronic pain on the spouse has typically relied on the use of standardized, objective self-report measures. While much has been learned using self-report measures there are limitations connected with it. Self-report measures, while efficient, may be limited in their scope of inquiry. Thus the domain of experience of spouses of chronic pain patients may remain untapped. A second problem is that this type of research exemplifies the investigation of constructs as defined by researchers rather than constructs as experienced by participants (Patton & Jackson, 1991). Thus, our current understanding of the impact on the partner of a chronic pain sufferer may be biased by the theories and definitions that have been applied the problem. Concept mapping is a method unrestricted by theoretical or constructual bias that enlarges the scope of inquiry and is consequently a relevant research alternative. A further unique and helpful product of concept mapping is the identification of themes which are visually depicted in maps.

No research utilizing concept mapping methodology has been applied to the problem of understanding the experience of female spouses of CLBP sufferers. The

current study will utilize concept mapping methodology, results of which will likely be a helpful addition to the existing literature by enlarging understanding of the impact on and coping of CLBP spouses. It will, in addition, identify and visually present themes in an easily understood map.

CHAPTER 3: METHOD

A review of the literature related to the impact of chronic pain on the spouse and family indicated a need to examine the issue using methods less constrained by the limitations of objective measures and researcher bias. The concept mapping methodology utilized in the present study is an approach that combines qualitative and quantitative research strategies useful for representing the perceptions and experiences of research participants. The results of such research might compliment the previous literature and may be used to develop new therapeutic programs to assist spouses manage the challenges of living with a chronic pain sufferer.

This research followed the six steps outlined by Trochim (1989b) to derive the domain of experience and concept maps reflecting what it was like to live with a partner with CLBP. Five of these steps are contained in Phases One and Two of this research. In Phase One, the research question was formulated, participants were selected, and the participants generated statements about the research question. In Phase Two—Structuring of Statements, the interrelationships between the statements were articulated by having a groups of participants sort the statements into sets containing a common theme (categorization of statements). Multivariate statistical techniques were applied to this information to determine underlying themes which were then assigned labels (interpretation of maps). The concepts generated were visually depicted in the form of a map (representation of statements). The utilization of maps is depicted in Chapter 4 of this document. In addition to the concept mapping process outlined by Trochim (1989b), this study had a third major phase designed to determine the magnitude and commonalty of the experiences identified in Phase One. In Phase Three—Rating Survey, participants rated the statements generated in Phase One according to the degree to which the statements were true of their experience.

Phase One: Generation of Statements

The purpose of phase one was to collect a list of statements that would describe the experience of living with a chronic low back pain sufferer (CLBP) sufferer. A WCB rehabilitation population was selected to investigate the affects of CLBP on female spouses. The study was approved by the WCB Research Committee and the Educational Psychology Ethics Committee. Six hundred and twenty-four names were obtained from the Workers' Compensation Board-Alberta Rehabilitation Center client file using the following criteria: attendance at the Rehabilitation Center since 1990, low back injury, length of injury at least six months, male clients, married, and address available. Two-thirds were randomly selected for inclusion in this study. Of these 416 names, 156 were randomly selected for inclusion in Phase One of this research. A package containing a cover letter describing the study (Appendix A), demographic survey (Appendix B) and questionnaire (Appendix C) was mailed to this group. Participants in this phase of research were asked to respond with written statements to the question, "What is/was it like for you to have a partner in chronic low back pain?" Statements of 10 participants were collected and transcribed. Another four participants contributed statements; those which were new were transcribed. Finally, redundancy was reached as an additional four statement lists were collected but contributed no new statements.

Phase Two: Structuring of Statements

Eleven participants who had volunteered from Phase One were mailed sorting kits. The kits contained a cover letter on WCB letterhead (Appendix F) that explained the nature and purpose of the study, the voluntary and confidential nature of the study and participant ability to withdraw from the study at any time. The bottom portion of the letter described a three-step sorting procedure. Participants were asked to read the 70 statements and sort the statements into groups that made sense to them. There responses

were recorded on the statement sort recording sheet (Appendix H). Participants also completed a brief demographic survey (Appendix G).

Participants who returned rating surveys were given the opportunity to volunteer to do sorts. Forty of the 71 rating participants were subsequently mailed sorting kits similar to those received by the first group of volunteers (Appendices F, G, H).

Data Analysis

Descriptive statistics were computed on the data provided by sorters on the demographic survey, including means, range and percents. The sort data were analyzed following the procedures outlined by Trochim (1989b) and summarized in Chapter 2 in the sections; generation of statements, structuring of statements and representation of statements.

A number of cluster solutions (i.e., number of clusters) were inspected by the author and supervisor to determine the most interpretable cluster solution. Consensus was reached on the naming of the clusters of the accepted seven cluster solution. This cluster solution was further analyzed to determine any sensible clusters of clusters.

Phase Three: Rating Survey

The 70 statements of Phase One were made into a questionnaire (Appendix K) and mailed to 396 women (416 minus 20 names returned by the post office).

Participants of this phase received a cover letter (Appendix I) on WCB letterhead which explained the nature and purpose of the study, the voluntary and confidential nature of the study and participant ability to withdraw from the study at any time. The cover letter also contained rating instructions. Participants were to rate each statement on the two-page survey according to the degree to which they agree. The scale was 1 to 5 with 5 indicating that they strongly agreed with the statement. A 5 response would thus indicate that they had experienced what was reflected in the statement to a great degree. They could also indicate when a statement did not apply (na) to them. Participants also

completed a brief demographic survey (Appendix J). Participants were further asked to provide statements that reflected their experience but which were not included in the 70 statements of the survey.

Data Analysis

These data were subjected to a series of statistical procedures. First, the frequencies for each statement were determined. That is, the percent of endorsement (i.e., 1-5 and na) was calculated for each value for each statement. Prior to calculation of means, however, values were reversed (i. e., 1=5, 5=1) for the nonnegative statements (39, 42, 43, 21, 44, 20, 15, and 14). The mean of values 1 through 5 for each statement was then calculated and ranked by descending mean. The percentage of participants who agreed with each statement (i.e., endorsed 3, 4 , 5) was calculated for each statement. Seventy-five percent agreement was arbitrarily assigned as the cut-off for inclusion of statements reflecting common experience. This list also included highly-negative statements (3.89 or higher) and highly--positive statements (2.03 or less).

Posthoc one-way analysis of variance were run on three variables using the Tukey-HSD test at the 0.05 level. The severity of impact of living with a CLBP sufferer was compared based on pain severity, duration of pain and presence of children in the home. Finally, the additional statements which seemed redundant, appeared to be represented by others, or were listed on the original survey were removed (Appendix M).

CHAPTER 4: RESULTS AND DISCUSSION

The purpose of the present study was to gain a better understanding, using concept mapping, of the experience of female spouses of chronic low back pain (CLBP) sufferers. The author also sought to determine themes underlying spouses' experience. A further purpose was to determine which of the experiences were most common and/or prominent. Finally, the author investigated impact differences based on pain severity, pain duration, or presence of children in the home. Specifically, the results of the three phases of the study correspond with the three research questions. First, the statements written by spouses reflect their experiences of living with CLBP sufferers. Second, the structuring of these statements elucidated the themes underlying the experiences identified by spouses. Third, the rating survey provided information on the incidence of these experiences in a larger group of spouses of CLBP sufferers.

Phase One: Generated Statements

One hundred and fifty-six letters were mailed to prospective participants, 20 were undeliverable by the postal service and, 14 completed response forms were received and compiled. Subsequently, four more responses were received. See Table 1 for characteristics of the 14 respondents.

Table 1

Characteristics of Statement Generation Participants

Characteristic	M	Range
Age in years	49	23-56
No. of years living with partner	14	3-40
No. of children at home	1.71	0-4
No. of months partner in pain	79	14-204
No. of months partner pain treatment	70	7-204

Note. The n =14.

The age of the participants ranged from 23 to 56 years with a mean age of 40 years. Two of the respondents were in their 20s, 5 were in their 30s, 5 were in their 40s and 2 were in their 50s. Length of time living with their partner ranged from 3 to 40 years with a mean of 14 years. Ten of the 14 women had children living at home. Length of time their partner's had been in pain ranged from about 1 to 17 years with the mean of 6 years. Length of pain treatment closely parallels time in pain and ranged from 7 months to 17 years with a mean of 5.8 years. Half of the respondents had been involved in their partner's pain treatment, while 71% would like to have been included.

Fourteen respondents yielded 114 statements (Appendix D). No new statements were added by the final four respondents, thus redundancy was achieved. This list was reduced to 100 by discarding unclear statements or those which duplicated the meaning of other statements (Appendix E). The master list of 70 statements was arrived at using the same process and was further refined by extracting the central idea (Table 2). Extraction was a process of retaining the essential words from respondents' longer statements. Further, a second researcher compared the original statements with the final statements as a check to ensure the essence of the original statements was retained. See Table 2 for the master list of 70 statements.

Seventy statements reflecting the experience of 14 participants were generated in Phase One of the study. The statements suggest that the experience of living with a chronic pain sufferer is pervasive and almost entirely negative. Of the 70 statements, only four were judged positive (14, 15, 20, 21), while four others were considered neutral (39, 42, 43, 44). The 70 statements were used to develop the concept map and rating survey in Phases Two and Three.

Table 2

Statements Grouped in Seven Clusters by Descending Bridging Index

[a]No	[b]R	Statements	Percent Endorsing 1-5, na [c]1	2	3	4	5	[d]na	M	SD	[e]BI
		Cluster 1—Depression/Isolation									
61	62	I take on jobs or activities just to stay way from home.	34	23	11	7	7	17	2.16	1.29	.00
30	36	I feel guilty for being angry.	13	16	17	13	28	14	3.33	1.47	.03
55	50	I feel all alone, wanting so badly for some support.	27	14	21	10	17	10	2.73	1.48	.03
24	24	I get tired more easily now.	4	20	16	20	34	8	3.64	1.30	.05
28	26	I now do more things alone.	11	13	16	18	37	5	3.60	1.43	.05
53	44	I try desperately to handle severe depression.	17	17	18	11	20	17	3.00	1.46	.05
11	45	Resentment and sorrow make up a good portion of my life.	24	13	18	16	20	8	2.94	1.51	.05
1	1	I was frustrated because I couldn't do anything about his pain.	1	1	6	14	76	1	4.64	.78	.06
37	27	My emotions and frustrations are bottled up inside me.	11	17	13	16	39	4	3.57	1.47	.08
29	48	It bothers me that I have to get up and go to work and he doesn't.	24	11	11	7	17	30	2.74	1.60	.09
49	34	I put my feelings on hold until I know what kind of a day he is having.	12	17	16	13	30	5	3.37	1.47	.11
45	30	I feel that all the responsibility has fallen on my shoulders.	7	17	21	21	32	1	3.56	1.30	.17
2	35	I became lonely when we stopped seeing all our friends.	7	11	27	20	17	17	3.35	1.21	.20
23	6	I worry about him all the time.	3	7	16	11	63	0	4.25	1.13	.22
56	37	My sleep pattern is much disturbed.	14	16	17	14	28	10	3.30	1.48	.23
50	22	I find life is very unstableand full of turmoil.	9	13	24	10	41	4	3.65	1.38	.26
68	20	I find myself fed-up with the whole situation, at times.	9	11	18	18	35	7	3.66	1.35	.28
3	8	I was sad because our lives were turned upside down.	3	4	14	24	55	0	4.24	1.04	.35
							Cluster Average		3.48	.91	.13

Table 2 (continued)

[a]No	[b]R	Statements	Percent Endorsing 1-5, na [c]1	2	3	4	5	[d]na	M	SD	[e]BI
		Cluster 2—Coping									
[f]39	68	I've had to learn to do things differently.	47	27	20	6	0	1	1.84	.94	.26
[f]42	66	I have learned to live with pain of necessity.	39	28	18	6	1	3	1.94	1.01	.34
[f]43	69	I deal with situations as they arise, one day at a time.	54	28	14	0	4	0	1.73	1.00	.35
[f]21	67	I've learned patience and compassion for others, especially my partner.	47	25	18	6	1	3	1.87	1.01	.45
[f]44	64	I take comfort in that things could be worse.	44	28	16	7	6	0	2.03	1.18	.47
[f]20	60	I find that talking and sharing comfort us.	34	23	27	11	3	1	2.25	1.14	.57
[f]15	41	Our pain is gradually healing.	10	23	24	21	16	8	3.11	1.25	.71
							Cluster Average		2.11	.59	.45
		Cluster 3—Severe Couple Disruption									
52	59	I can't be understanding and supportive anymore.	34	30	11	11	7	7	2.28	1.28	.02
48	42	I walk on eggshells, never knowing what to expect.	17	20	21	14	23	5	3.06	1.43	.10
69	53	I feel like walking away.	35	17	16	6	16	10	2.43	1.50	.13
46	54	I feel very lonely, we now avoid each other.	31	21	14	10	10	13	2.38	1.38	.16
27	55	I've started to treat him like a child.	31	24	16	11	9	10	2.36	1.33	.20
47	57	I feel like I'm with a stranger who has become a miserable child.	28	27	17	6	10	12	2.34	1.31	.22
7	49	I am embarrassed to watch my husband crawl from point A to B.	17	24	10	7	16	23	2.73	1.47	.22
35	7	I worry about his general health.	1	9	14	16	61	0	4.25	1.08	.24
8	56	I lost trust in him when he'd steal pain pills.	16	10	4	4	6	58	2.36	1.47	.25
							Cluster Average		2.75	.97	.17

Table 2 (continued)

[a]No	[b]R	Statements	Percent Endorsing 1-5, na						M	SD	[e]BI
			[c]1	2	3	4	5	[d]na			
		Cluster 4—Focus on Pain Sufferer									
59	52	My husband is constantly yelling and screaming.	24	20	24	7	14	10	2.64	1.38	.22
60	61	His loudness creates my constant headaches.	32	18	16	4	7	21	2.16	1.29	.25
32	51	I worry about him mixing alcohol with medication.	23	6	4	3	16	47	2.67	1.77	.29
64	38	He is always complaining about the pain.	13	17	25	17	25	1	3.26	1.37	.31
31	28	He used to be easy going, now he is bitter.	11	7	27	16	34	0	3.57	1.36	.38
54	65	I am afraid to leave my partner alone in case of suicide.	47	9	7	4	10	23	1.98	1.46	.38
67	63	He is spending too much time eating and is getting overweight.	25	32	16	3	6	14	2.16	1.12	.41
25	58	He always thinks I am going to leave him.	38	11	14	10	9	18	2.30	1.42	.46
16	32	I feel concerned that my partner denies his physical limitations.	13	10	20	21	27	10	3.44	1.39	.48
							Cluster Average		2.77	.87	.35
		Cluster 5—Countercoping									
4	3	We did not know what to do.	4	3	11	13	64	5	4.36	1.10	.47
66	31	The worse the pain gets the less the doctors or WCB or anyone will help.	13	20	11	10	38	6	3.45	1.54	.51
38	15	Dealing with WCB put undue stress upon the whole family.	11	7	11	7	61	3	4.01	1.45	.52
5	11	The situation drained us financially.	7	7	4	23	52	7	4.14	1.26	.58
51	23	Neither of us can find the assistance we need.	11	13	13	14	39	8	3.64	1.47	.59
6	14	We had no money to have fun.	6	7	13	18	49	6	4.06	1.24	.64
40	5	I felt as though we were being judged by WCB.	7	7	7	10	68	1	4.26	1.28	.66
							Cluster Average		3.96	1.02	.57
		Cluster 6—Pain Focus									
33	16	I feel that since his injury our life has been put on hold.	4	14	11	13	51	7	3.99	1.31	.20
70	18	I feel angry at the system.	16	4	7	14	54	5	3.91	1.53	.50
10	2	It is difficult to look forward knowing the pain will always be there.	1	3	16	17	61	1	4.36	.95	.52
9	9	The pain is of priority in all aspects of our daily living.	4	10	6	21	58	1	4.20	1.19	.57
19	12	Our love making has been challenged.	3	11	14	18	52	1	4.07	1.18	.76
[f]14	13	Support from the WCB pain management course strengthened me.	4	4	3	4	27	55	4.07	1.44	1.00
							Cluster Average		4.07	.93	.68

Table 2 (continued)

[a]No	[b]R	Statements	Percent Endorsing 1-5, na [c]1	2	3	4	5	[d]na	M	SD	[e]BI
		Cluster 7—Relationship Disruption									
18	47	Friends and family could not show compassion for my partner.	24	24	13	16	19	7	2.79	1.48	.30
13	10	He has needed much attention andencouragement from me.	1	7	16	24	51	1	4.17	1.04	.32
36	29	The children experience much pressure.	7	17	17	13	34	12	3.57	1.39	.33
12	33	Our children and I have become victims of his anger.	17	9	17	17	31	9	3.41	1.51	.33
26	39	His family and friends stop asking for help.	9	20	21	16	20	16	3.22	1.32	.35
65	21	It seems as the years go by he is getting worse and worse.	9	14	17	16	38	4	3.57	1.47	.36
58	25	When he is in pain, everyone is in pain and suffers.	13	10	20	14	41	3	3.62	1.45	.38
17	4	Fears escalate as pain has not improved with surgery.	0	7	7	7	39	41	4.30	1.08	.38
62	46	He withdrew from us.	23	18	17	17	14	10	2.79	1.43	.40
34	40	We argue more than we ever did before.	11	30	16	10	28	5	3.15	1.45	.43
57	43	My partner is not involved with the children as much.	17	17	17	16	20	13	3.05	1.45	.44
63	70	He has left us.	35	4	3	0	4	49	1.58	1.23	.46
41	17	The side effects on the family is as painful as the pain itself.	6	11	16	17	49	1	3.94	1.28	.51
22	19	The constant cruel pain takes away from every member of our family.	4	17	13	17	48	0	3.87	1.30	.53
							Cluster Average		3.43	.89	.39
							Total		3.24	.73	

Note: The n of statement generation was 14. Generation resulted in 70 statements. The n of the rating survey was 71.

[a] Number of the statement.

[b]Rank of the statement based on M, the higher the M the lower the number. The higher the M the more problematic the statement or cluster.

[c]1=strongly disagree, 2=disagree, 3=slightly agree, 4=agree, 5=strongly agree

[d]na=not apply.

[e]Bridging Index. Lower BI indicates that the statement was more consistently grouped with certain statements.

[f]These values were reversed prior to M calculation of nonnegative statements (39, 42, 43, 21, 44, 20, 15, and 14).

Phase Two: Structured Statements

This phase was designed to provide information about how the statements are related to each other. The initial step in this phase was sorting of the 70 statements by 21 spouses of CLBP sufferers. The participants sorted statements into groups that made sense to them, entered the groupings on a recording form and assigned labels to the groups. The numbers of groupings ranged from 4 to 17. The completed sort data were entered into the Concept Mapping computer program (Trochim, 1993) for computation on a chain of subanalyses including an aggregation routine and map computation. Entered sort data initially resulted in a matrix for each individual. The aggregation routine provided a group binary symmetric matrix collected from the individual matrices. In this way the relational structure of the participants' experiences was presented. A high value in a matrix indicated that several participants placed a particular pair of statements in the same group and implies that the statements are conceptually similar in some way.

Table 3 shows the characteristics of the participants. Thirty-three percent of these participants had been involved in their partner's treatment while 72% would like to be. None of these spouses had received psychological support or treatment as a result of their experience with CLBP in their partner.

Table 3
Characteristics of Statement Sort Participants

Characteristic	M	Range
Age in years	43	23-56
No. of years living with partner	21	5-40
No. of months partner in pain	82	14-204
No. of months partner pain treatment	67	0-204
Impression of partner's pain level	8.09	[a]4-10

Note. The n of statement sort participants was 21.

[a]The scale ranged from 1 to 10, the higher the number the more severe the pain.

The 21 sorters were derived in the following manner. Six of the 11 who had volunteered from Phase One returned completed sorts. One sort was not included in the study as instructions were not followed correctly. This participant grouped the statements according to whether she had experienced what was described in the statement. The other 16 sorters were obtained from a group of 40 who had volunteered from the Rating Phase and who had subsequently responded.

Concept mapping organized the data so that it could be represented in meaningful and interpretable formats. The first format was a point map that located each statement as a separate point where those points which were placed closer to each other were likely to have been sorted together more frequently. To accomplish this, a two-dimensional nonmetric multidimensional scaling (MDS) of the group similarity matrix was conducted. This process converted the matrix representing the spouses' sorts and iteratively placed points (statements) at distances on a bivariate distribution which best reflected their similarities. The computer ran 15 iterations, each improving on the previous point arrangement as measured by the stress value for each iteration. The stress value is an index of stability of an MDS solution that ranges from 0.00 (perfectly stable) to 1.00 (perfectly unstable). The final stress value for the two-dimensional MDS of this data was .2853 which suggests that this solution was reasonably stable. This stress value was comparable to other research using concept mapping methodology, such as .27 (Daughtry & Kunkle, 1993; and Knish, 1994), .31 (Trochim, Cook & Setze, 1994), and .32 (Miller, 1996).

Inspection of the point map of this study (Figure 1) showed there were two groups of statements that were so closely placed that they were virtually on the same point. Statements 1 (I was frustrated because I couldn't do anything about his pain), 55 (I feel all alone, wanting so badly for some support), and 28 (I do more things alone) were located closely. Statements 31 (He used to be easy going, now he is bitter), 59 (My husband is constantly yelling and screaming), and 64 (He is always complaining about the pain)

Figure 1. Point map of the 70 statements.

were located closely. On the left side of the map, Statements 5 (The situation drained us financially) and 6 (We had no money to have fun) were closely placed. The proximity of these statements imply a high degree of similarity.

Cluster Analysis

A hierarchical cluster analysis on the MDS solution (Figure 1) was run. Trochim (1989b) suggests that a "true partitioning of space" (p. 9) is achieved for cluster solutions that do not have overlapping clusters, exhibit fragmentation or overgeneralize.

While the decision as to the numbers of clusters was at the discretion of the researchers, computation of the "bridging index" assisted in this determination and subsequent naming (Trochim, 1993). The bridging index ranges from 0.0 to 1.0. Lower values represented statements frequently sorted together while higher values reflected statements that were more frequently sorted with statements farther away on the map. The bridging index is also useful in the naming of clusters. The lower the bridging index, the more central the statement was for the meaning of the cluster. An average bridging for each cluster was also calculated. Clusters with low average bridging values were more likely to represent a coherent set of statements that were easier to label. Clusters with higher bridging averages were more likely to be "linking" clusters which acted as bridges between adjacent clusters (Trochim, 1993). Information from bridging indices, statement and cluster, was utilized to help determine the most appropriate number of clusters.

Solutions with 14, 10, 9, 8 and 7 (Appendices N, O, P, Q, Table 2, Figure 2) clusters were analyzed in order to determine what grouping made the most sense. The optimum solution was determined to include seven clusters (Figure 2 and Table 2). Fragmentation and overgeneralization were judged to be minimized in this solution. Clusters were labeled by the researchers by analyzing the content of each cluster conceptually and with the help of bridging indices.

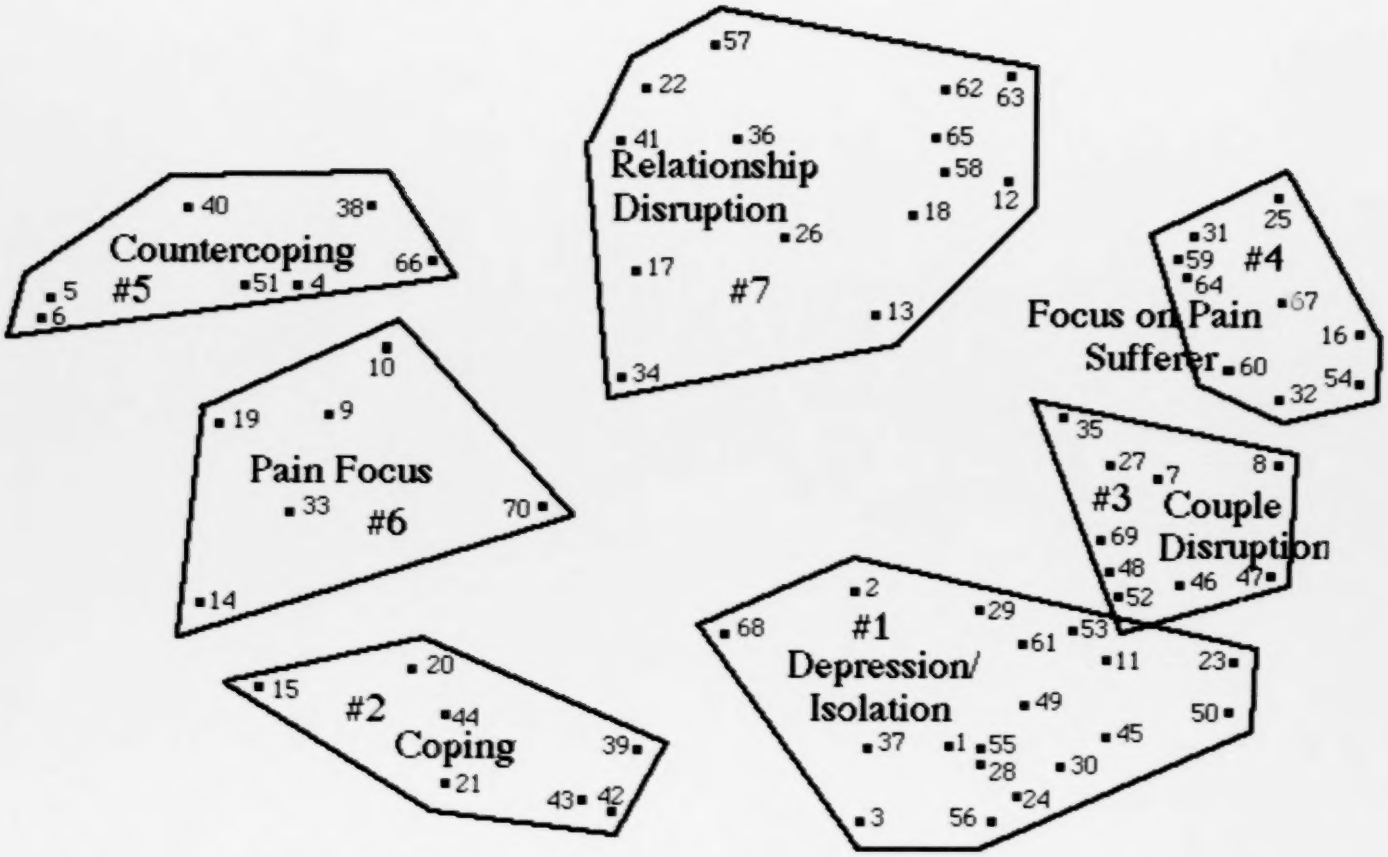

Figure 2. Seven solution cluster map.

Description of Clusters

Cluster 1—Depression/Isolation. Cluster 1 had a low bridging index (0.13) which suggested high conceptual similarity among statements. Depression was unmistakably evident in the words used by the participants in 13 of the statements in this cluster: bottled up emotions, sad, tired, guilty, angry, disturbed sleep, bothered, fed-up, resentment, sorrow, desperate, severe depression, worry, unstable, and turmoil. Statement 1 (I was frustrated because I couldn't do anything about his pain) implied helplessness which is commonly linked to depression.

Isolation is reflected in five of the statements: "I feel all alone . . . ," "I now do more things alone," "I became lonely when we stopped seeing our friends," "I take on jobs or activities just to stay away from home . . . ," and "I feel that all the responsibility has fallen on my shoulders."

The picture painted by the statements in this cluster depicted the loneliness, isolation and emotional turmoil, especially depression, experienced by women living with CLBP sufferers. The fact that 18 statements are included in this cluster demonstrated the variety and breath of intrapersonal experience and highlighted the prominence of depression as a consequence of living with a chronic pain sufferer.

Cluster 2—Coping. Cluster 2 was the only cluster with a positive bent. Statements in this cluster suggested that, for some, the experience of living with a CLBP sufferer could be a learning experience. The learning may have been a neutral experience as was reflected in Statements 42 (I've learned to live with the pain . . .) and 39 (I've had to learn to do things differently) or positive, as in Statement 21 (I've learned patience and compassion . . ." Some spouses used coping strategies to obtain comfort. For some, talking and sharing was comforting, while for others, comfort was recognizing that things could be worse. Statement 43 indicated that to cope with the situation of living with a chronic pain sufferer, taking one day at a time was helpful. The statement, "our pain is

gradually healing" (15) was different than the other statements in the cluster in that it was not an adaptive measure performed by the participants, but was certainly an experience that could facilitate coping. Despite the bridging index, apparent conceptual similarity rendered it an easy cluster to label.

Cluster 3—Severe Couple Disruption. Cluster 3 had a relatively low bridging index (0.17) suggesting conceptual similarity among statements. Indeed, the statements reflected negative changes in the marital relationship, even marital disruption. A loss of dignity and trust in the relationship was suggested in ". . . embarrassed to watch my partner crawl . . ."(7), "I've started to treat him like a child" (27), and " I lost trust in him when he'd steal pain pills" (8). Apprehensive unpredictability was reflected in the statement, "I walk on eggshells, never knowing what to expect" (48). Loneliness from loss of closeness in the relationship was suggested in Statement 46, " I feel lonely, we now avoid each other". Emotional distance may degenerate to relationship fatigue (I can't be understanding and supportive anymore, Statement 52) and eventually lead to thoughts of giving up (I feel like walking away, Statement 69).

Statement 35 (I worry about his general health) had one of highest bridging values in this cluster (0.24) and seems to be qualitatively different than other statements. This statement was found in the far upper left corner of this cluster. Its location between Clusters 4 and 7 may indicate that this statement may have been sorted with other statements in these clusters and may thus be conceptually similar to these.

Cluster 4—Focus on Pain Sufferer. Statement 35 seemed to fit well into this cluster which contains other statements of focus and concern for the chronic pain sufferer, prominently the pain sufferer's behavior. Half of the statements in this cluster (16, 54, 67, 32) have to do with behavior which is potentially harmful to the himself, i.e., ". . . partner denies physical limitations . . .", "in case of suicide," ". . . too much time eating and is getting overweight . . .," and ". . . mixing alcohol with medication." The remaining

statements described behaviors more likely to impact the day-to-day life of his spouse. His loudness (60), yelling and screaming (59), constant complaining (64), bitter disposition (31) and fear of being left (25) were behaviors likely to make life substantially unpleasant for the partner and result in such negative consequences as constant headaches (60).

Overall, these statements painted a picture of a partner potentially consumed by concern for the well-being of the CLBP sufferer with whom they live, on one hand; while on the other, the partner was the hapless recipient of the sufferer's rage and fear.

Cluster 5—Countercoping. Early inspection of Cluster 5 indicated the presence of two unrelated groups of statements. Statements 5 and 6 clearly had to do with the financial hardship of living with CLBP. The other statements in the cluster were related to support issues. Statements 4 and 51 suggested an inability to get needed support, thus the CLBP couple were left to try to manage the situation on their own. What might be termed countercoping (factors which made matters worse) were described in statements 40, 38, and 66. These statements all concern WCB and suggest that judgmental treatment "put undue stress on the whole family" (38).

A composite depiction of the experience in this cluster was that couples may not be able to access support and that WCB not only failed to provide support but compounded the stress of living with CLBP sufferers. The conceptual similarity between financial hardship (statements 5 and 6) and the support-related statements in this cluster is depicted in the label, Countercoping. It seems likely that financial hardship, lack of support, and WCB conflict might work against coping.

Cluster 6—Pain Focus. This cluster was the most heterogeneous on the map with a bridging index of 0.68. Two of the statements were clearly odd. Statement 14 (support from WCB pain management course strengthened me) seemed to be conceptually irrelevant to the cluster. Its bridging index was 1.00 indicating that while it was placed in

this cluster it was frequently sorted with statements further away on the map. The statement's proximity to and its conceptual similarity may occasion Cluster 2 as an appropriate alternative placement. Statement 70 (I feel angry at the system) is located in the far right hand corner of this cluster and is located approximately half way between clusters 1 and 5. It is possible that it may have been sorted with the affect-related statements in Cluster 1 and the WCB-related statements in Cluster 5.

Statement 19 (Our love making has been challenged) had a high bridging index (0.73) and may have been sorted with distant statements of seemingly greater similarity such as Clusters 3 and 4. Nonetheless ,the statement could be woven into the theme of Cluster 6.

The meaning of this cluster can be summed up in the phrase, "where we once had a life, we now have pain." Specifically, the absence of normal life was suggested by the statements, "our life has been put on hold" (33) and "our love making has been challenged" (19). Pain as a replacement for life was indicated in the statements, "pain is of priority in all aspects of our daily living" (9), and "it is difficult to look forward knowing the pain will always be there" (10).

Cluster 7—Relationship Disruption. Disruption of interpersonal relationships seemed to be the theme of Cluster 7. Relationships touched by the experience of CLBP include those of the partner, children, nuclear family, extended family and friends. Arguing (34) and increased demands for time and emotional strength (13) were experienced by the partner. Partner and children were "victims of his anger" (12). Children ". . . experience much pressure" (36), at the same time, did not benefit from as much time with their fathers (57).

Statements such as: "when he is in pain, everyone is in pain and suffers," "the constant cruel pain takes away from every member of the family" (22), and "the side effects on the family is as painful as the pain itself" (41), connoted the pervasiveness and

severity of impact on the family unit of living with a CLBP sufferer. Further, it seemed that the situation may lead to the breakdown of the couple and nuclear family unit "he withdrew from us" (62), and "he has left us" (63).

Finally, the deleterious impact of chronic pain extends outside the nuclear family to affect extended family and friends as well, "friends and family could not show compassion for my partner" (18), and "his family and friends stopped asking for help", (26)]. Personal relationships, it seems, suffer in the presence of CLBP.

Regional Interpretation of Concept Maps

A higher level analysis of the MDS solution involved determining "whether there were any sensible groups or clusters of clusters" (Trochim, 1989b, p. 11). The map was vertically partitioned into two regions (Figure 3). The left side of the map, Clusters 2, 5, and 6, appeared to represent factors which either caused, exacerbated or remediated the problems related to living with a chronic pain sufferer. Cluster 6 represented the cause—Pain, the almost personified and certainly unwelcome intruder which dominates the present and clouds the future. Pain (Cluster 6) was sandwiched between two clusters representing polar regulators of the pain focus. The cluster beneath, Coping (Cluster 2), contained statements which may be helpful in remediating the effects of pain, such as: a gradual healing of pain (15), the use of coping strategies (44, 20, 39, 42, and 43), and personal growth (21, I've learned patience and compassion . . .). Cluster 5, located above Pain (Cluster 6), had statements which would likely exacerbate the problem by either adding to the problem [i.e., stressful dealings with WCB (40, 38, and 66) and financial distress (5 and 6)] or by simply failing to get support and assistance (4 and 51).

The right side of the map appeared to be composed of statements and clusters indicative of the consequences of the pain problem and related unsuccessful resolution of the struggle between Coping and Countercoping (Clusters 1, 3, 4, and 7). The right side of the map was further divided, horizontally, to depict two broad categories of outcome:

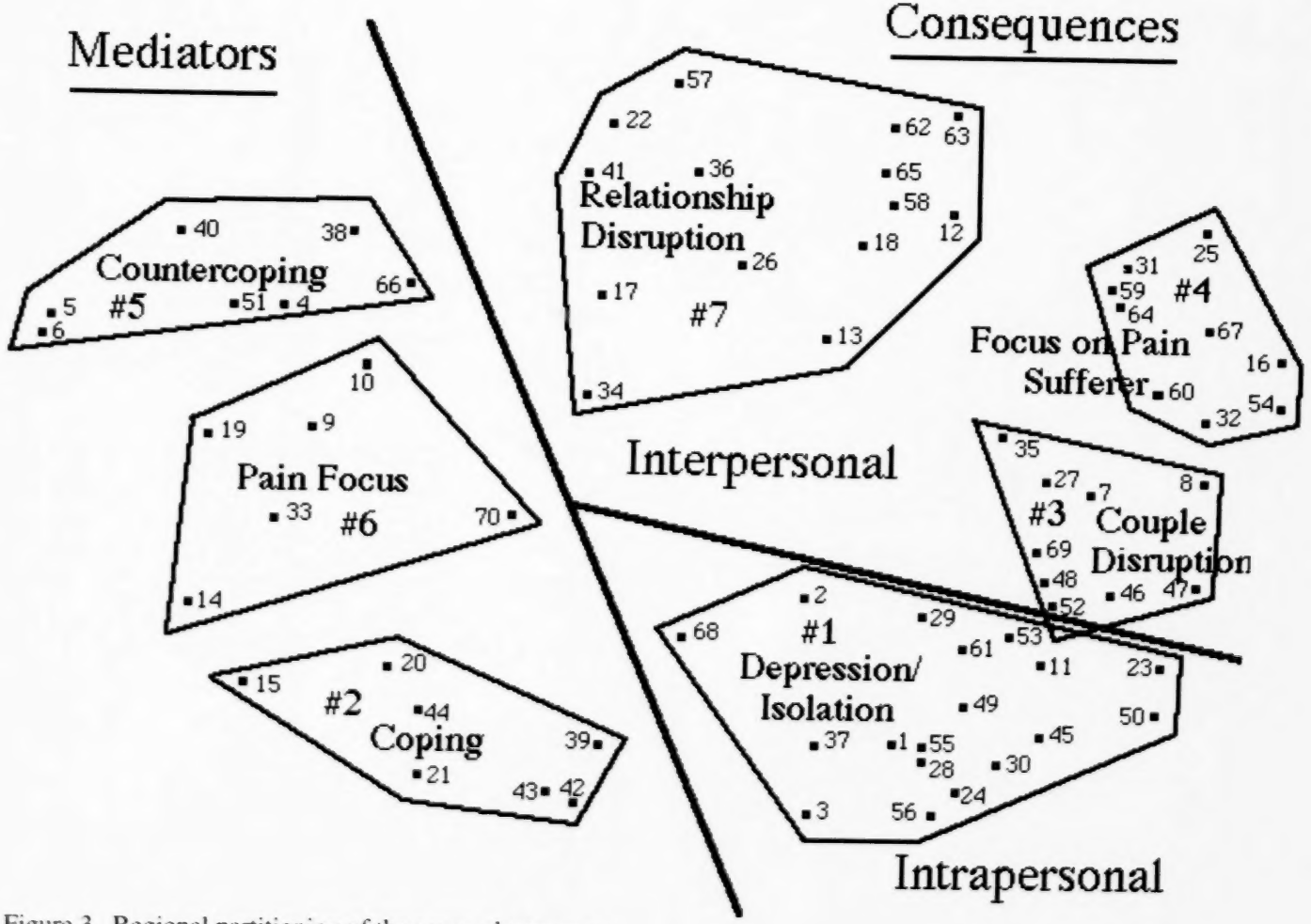

Figure 3. Regional partitioning of the seven cluster map.

intrapersonal (Cluster 1) and interpersonal (Clusters 3, 4, and 7). Intrapersonal effects were largely related to depression with its related symptomotology and secondarily to isolation and loneliness. The interpersonal product of pain included disruption of a number of relationships (i.e., couple—Cluster 3; child, nuclear family, extended family and friends—Cluster 7) and the expense of concern and focus by the partner for the chronic pain sufferer (Cluster 4).

Phase One produced a list of 70 statements which reflected the experience of living with a CLBP sufferer. Phase Two produced a map which arranged these statements into conceptually similar clusters. While these two phases described the experience of 14 spouses of CLBP sufferers neither reflected which experiences were most common or important.

Phase 3: Rating Survey

The individual experiences of the participants who contributed the original statements are documented in the master statement list (Table 2). What this list does not reflect is the relevance each statement of experience had to a broader group of participants. This survey sought to answer the third research question, "What is the incidence of these experiences in a larger group of spouses of CLBP sufferers?" It was conducted to determine which of the original statements more commonly reflected the experience of living with a chronic pain sufferer. This portion of the research also sought to discover if experience differed based on presence of children at home, length of time the partner had been in pain, or perceived level of the sufferer's pain.

A survey instrument was created using the 70 statements from Phase One of this research (Appendix K). This was accompanied by a 9-item demographic survey (Appendix J) and was mailed to 396 participants. Seventy-seven responses were returned within the month allotted for completion. Six surveys were rejected as participants failed to complete the second half of the survey. Data from the remaining 71 surveys were

statistically analyzed. Nonnegative statements were recoded so that the value labels were reversed (i.e., 1=5). Frequencies were calculated on the 70 statements and demographic responses. The frequency for each value label [not apply (na), strongly disagree (1), disagree (2), slightly agree (3), agree (4), and strongly agree (5)] for each statement was calculated. Next, a mean for each statement (Table 2) and relevant demographic data (Table 4) were obtained. In addition to the data presented in Table 4, 30% of participants indicated that they had been involved in their partner's treatment while 65% would like to have been. Seven percent of spouses had received psychological support related to the experience of CLBP in a partner.

Table 4

Characteristics of Rating Survey Participants

Characteristic	M	Range
Age in years	43	24-61
No. of years living with partner	20	4-43
No. of children at home	1.5	0-6
No. of months partner in pain	80	6-480
No. of months partner pain treatment	80	0-420
Impression of partner's pain level	7.77	[a]1-10

Note. The n =71.

[a]The scale ranged from 1 to 10, the higher the number the more severe the pain.

For the statements, higher mean (M) denoted unfavorable experience. The statements were then ranked by descending M and included in Table 2. For each cluster, a M of its statement M was determined to compare the prominence of the experience described in each cluster. Group comparisons were made on several demographic variables.

Perhaps the overall finding of this part of the study was that the experience of living with a chronic pain sufferer is predominately negative. Of the 70 original statements, four were judged to be neutral (44, 42, 39, 43), four positive (14, 15, 20, 21),

and 62 negative. Survey participants largely agreed with neutral statements but agreed to only 2 of 4 positive statements. Forty-two negative statements were largely endorsed by participants.

Appendix R listed the M for all statements for each participant thus provided a measure of the severity of the experience by person. Nine participants had a strongly negative experience (4.13-4.59), another 33 had a clearly negative experience (3.00-3.99), five had a relatively positive experience (1.71-1.81) and another 23 were in between (2.12-2.97).

Table 2 and Appendix T are summaries of statistics of the responses for each statement on the survey. Frequencies for each value label for every statement, as well as, means and standard deviations are presented. Appendix S ranks the statements by descending means. Data indicated that surveyed participants at least slightly agreed with 44 of the 70 statements. Of these 44, 15 had a mean of 4.00 or higher indicating agreement or strong agreement. Means tend to be a measure of the magnitude of the experience and to a lesser degree express how common these experiences are among participants. For negative statements high means reflect agreement while for nonnegative statements low means reflect agreement.

Table 2 also includes the percentage of respondents for each statement who endorsed "slightly agree," "agree," or "strongly agree." This frequency statistic is a measure of commonalty with less emphasis of magnitude of the experience. When 75% was arbitrarily established for inclusion in a set representing the most common experiences, all but two of the top 15 statements ranked by mean were included. As well, an additional seven high mean (3.57-3.99) statements (33, 41, 70, 22, 58, and 31) were accepted (Table 5). Six nonnegative, low mean, high-agreement statements (mean 2.25-1.73, agreement 84-96%) were added to reflect significant common positive experiences for spouses living with chronic pain sufferers. Twenty-eight statements are included in

the top ranked list (Table 5) and they have means of 3.57-4.64 and 2.25-1.73 respectively and agreement ranging from 75%- 96%.

Two statements from the high-mean list do not have correspondingly high percentages. Statement 17 is ranked fourth by mean (4.30) but has a percent agreement of 53. This is because 41% of participants responded with "not apply" indicating that a high proportion do not have surgery as part of their experience but that for those who do, surgery is a strongly negative factor. Statement 14 (support from the WCB pain management course strengthened me) is ranked 13th (M=4.07) and had an 11% agreement. Fifty-five percent responded with "not apply" suggesting that most respondents did not participate in a pain management course. Eleven percent agreed that they were strengthened by support from the course while 31% disagreed. Of the participants who apparently experienced the pain management course, 26% benefited while 74% did not.

The top ranked statement (4.64) was endorsed by 96% of participants. "I was frustrated because I couldn't do anything about his pain" seems to be the most common and most strongly felt experience for the group and is found in Cluster 1. Also in Cluster 1 is the sixth ranked statement, "I worry about him all the time," (4.25) endorsed by 90% and the eighth ranked statement, "I was sad because our lives were turned upside down," (4.24) endorsed by 93%. A high percentage of respondents experience a high degree of frustration, helplessness, worry and sadness. As well, 75% ". . . find life very unstable and full of turmoil" (M = 3.65, ranked 22nd). Intrapersonal consequences, especially dysphoria, are prominent and common among participants.

Similarly prominent on the right side of the map is Cluster 7 with its 14 statements of which five were top ranked (17, 13, 41, 22, 58). The pervasive indiscriminance of the effects of chronic pain on others, especially family members, was illustrated in three statements: "the side effects on the family is as painful as the pain

Table 5

Extreme and/or Frequently Endorsed Statements by Descending Mean

[a]Rk.	No.	Statement	M	[b]% Agree
1	1	I was frustrated because I couldn't do anything about his pain.	4.64	96
2	10	It is difficult to look forward knowing the pain will always be there.	4.36	94
3	4	We did not know what to do.	4.36	88
4	17	Fears escalate as pain has not improved with surgery.	4.30	53
5	40	I felt as though we were being judged by WCB.	4.26	85
6	23	I worry about him all the time.	4.25	90
7	35	I worry about his general health.	4.25	91
8	3	I was sad because our lives were turned upside down.	4.24	93
9	9	The pain is of priority in all aspects of our daily living.	4.20	85
10	13	He has needed much attention and encouragement from me.	4.17	91
11	5	The situation drained us financially.	4.14	79
12	19	Our love making has been challenged.	4.07	84
13	[c]14	Support from the WCB pain management course strengthened me.	4.07	11
14	6	We had no money to have fun.	4.06	80
15	38	Dealing with WCB put undue stress upon the whole family.	4.01	79
16	33	I feel that since his injury our life has been put on hold.	3.99	75
17	41	The side effects on the family is as painful as the pain itself.	3.94	82
18	70	I feel angry at the system.	3.91	75
19	22	The constant cruel pain takes away from every member of our family.	3.89	78
64	[c]44	I take comfort in that things could be worse.	2.03	88

66	[c]42	I have learned to live with pain and its effects as a matter of necessity.	1.94	85
67	[c]21	I've learned patience and compassion for others, especially my partner.	1.87	90
68	[c]39	I've had to learn to do things differently.	1.84	94
69	[c]43	I deal with situations as they arise, one day at a time.	1.73	96

Note. The n is 71. Statements with means of 3.89 or higher are highly negative while those with means of 2.03 or lower are highly positive.

[a]Rk is the ranking of statements by descending means.

[b]% agree is the sum of participants endorsing 3 (slightly agree), 4 (agree), and 5 (strongly agree) for each statement.

[c] % agree for these statements is the sum of 1, 2, and 3 as values were reversed prior to M calculation.

itself" (3.94, 82%), "the constant cruel pain takes away from every member of our family" (3.89, 78%), and "when he is in pain, everyone is in pain and suffers" (3.62, 75%). Effects specific to the relationship with the partner were suggested in the tenth ranked statement, "he has needed much attention and encouragement from me" (4.17, 91%).

In contrast to these two right side clusters, statements in Clusters 3 and 4 were not as frequently or as strongly endorsed. One statement in Cluster 3 (Severe Couple Disruption) was found among those top ranked. "I worry about his general health" (4.25, 91%) was ranked seventh. This statement was qualitatively distinguished by its relative temperateness among a group of eight other more onerous relationship experiences. One statement was highly rated in Cluster 4, "he used to be easy going, now he is bitter" (3.57, 77%). Together, Clusters 3 and 4 reflect interpersonal consequences of greater affliction than those in Cluster 7, but compared to Cluster 7 appeared not to have been as commonly or strongly felt. Almost all of the statements on the left side of the map were highly endorsed by participants (16 of 20 statements). Clusters 6, 5 and 2 contained

statements which either cause, exacerbate or remediate inter and intrapersonal consequences found on the right side of the map.

Many participants commonly experienced intense pain focus in Cluster 6 as expressed by statements ranked second and ninth, "It is difficult to look forward knowing the pain will always be there" (4.36, 94%), and "the pain is of priority in all aspects of our daily living" (4.20, 85%). Eighty-four percent experienced a disruption in sexual relations (Statement 19, 4.07, ranked 12th), 75% "feel angry at the system" (3.91, ranked 18th), and 75% have "put their life on hold" (3.99, ranked 16th). The only statement in this cluster not endorsed was an incongruous positive statement regarding strength derived from the WCB pain management course.

Five of seven statements of Cluster 5 were generally endorsed. Eighty-eight percent expressed inability to obtain support in the third-ranked statement, "we did not know what to do" (4.36). WCB was depicted by 85% as a agent which might exacerbate the experience of chronic pain in the fifth ranked statement, "I felt as though we were being judged by WCB" (4.26). As well, 79% identified WCB as an additional source of stress in Statement 38 (4.01, ranked 15th). Financial distress was indicated by 85% and 84% of respondents in Statements 5 (4.14, ranked 11th) and 6 (4.07, ranked 14th).

Six of seven statements in the Coping Cluster (2) were often endorsed by participants. Eighty-five percent said they "have learned to live with pain and effects as a matter of necessity" (1.94). To accomplish this participants may have used at least one of the coping strategies described in four statements: "deal with situations as they arise, one day at a time" (1.73, 96%), "learn to do things differently" (1.84, 94%), "take comfort in that things could be worse" (2.03, 88%), and "find that talking and sharing comfort us" (2.25, 84%). Ninety percent of respondents said they had "learned patience and compassion for others, especially [their] partner" (1.87).

Another way to look at the data is to examine the statements to which participants agreed infrequently. Statement 63, "He has left us" was endorsed by seven percent suggesting sufferer-initiated marital breakdown occurred at that frequency for this group. Eleven percent agreed that "support from WCB pain management course strengthened [them], while 31% disagreed and 55% probably had not attended the course. Twenty-one percent were worried about suicide and 56% were not. Fourteen percent had lost trust in their partner when he'd steal pain pills. For this statement 58% indicated not apply. Another high not apply (47%) statement (56) suggested that mixing alcohol with medication was not a common practice, although 23% were worried about this. Finally, Statement 17 had 41% not apply, 53% agree, and 0% strongly disagree. This indicated that almost half of the group of sufferers had not had surgery, but for those who did it was largely an ineffective treatment for pain.

Cluster means were more extreme for the left side (2, 5, and 6) than the right side (1, 3, 4, and 7) of the map. Cluster 5 (Countercoping) had a mean of 3.96, Cluster 2 (Coping) had a mean of 2.11, and Cluster 6 (Pain Focus) had a mean of 4.07.

Clusters 1 (Depression/Isolation) and 7 (Relationship Disruption) had means of 3.48 and 3.24, both indicating general agreement with these experiences. Cluster 3 (Focus on Partner) and Cluster 4 (Marital Disruption) had, on the other hand, means of 2.75 and 2.77. These numbers were less than "slightly agree" and more than "disagree." It can probably be concluded that these more severe consequences as described in clusters 3 and 4 are not as commonly experienced as those in Clusters 1 and 7.

Group Comparisons

The severity of the impact of living with a CLBP sufferer was compared for three demographic variables: pain severity, time in pain, and presence of children (Appendix T). One-way analyses of variance were conducted posthoc using the conservative Tukey-HSD test at a significance level of .05. Participants rated their perception of the sufferer's

level of pain severity from 1 to 10 with high numbers being most severe. For the purpose of comparison 1 to 7 was considered mild, 8 was considered moderate and 9 and 10 severe. A significant difference was found between mild (2.75) and severe (3.59) pain severity (F=.0004). This suggests that when sufferer's pain was perceived by spouses to be severe, the negative effects of the pain experience were also experienced as severe by partners.

Impact severity was compared for three levels of pain time. A difference was found between Group 1 (1-36 months, 2.82) and Group 2 (37-120 months, 3.34). There was no difference indicated between Group 3 (over 120 months) and the other two groups. This suggests that consequences of living with a CLBP sufferer worsen over time until after several years its effects begin to decline. There was no difference in impact severity for participants with and without children suggesting that experience of living with chronic pain was not significantly more severe when children reside in the home.

Additional Statements

Opportunity was provided for survey respondents to contribute additional statements reflecting their experience that they felt were not covered on the formal survey. One hundred and five additional statements are included in Appendix L. Statements which seemed redundant, appeared to be represented by others, or were listed on the original survey were removed (Appendix M), leaving a list of 20 new statements (See Table 6).

Several of the additional statements seemed to be related to coping. Coping strategies included forgetting that things aren't the same (8), trying to accept it and being strong (14), becoming more self-sufficient (15), and not dwelling on it (18). Coping was facilitated by Canmore pain clinic (3), good family support and religious background (16), marriage counseling (17) and medical support (20). Additional intrapersonal effects

Table 6

New Additional Statements

No.	Statement
1	He suffered severe depression.
2	Due to the strain of everything regarding his pain and suffering, I could not take it anymore and divorced him.
3	Canmore pain clinic helped alot.
4	I find that since his injury we had to learn how to trust people all over again.
5	I have had to work two jobs to support the family.
6	I have experienced stress related illness since his injury.
7	My husband's self-esteem is gone. He believes he cannot support the family and feels useless.
8	I sometimes forget things aren't the same.
9	Not once did WCB or doctors involve me or even talk to me.
10	I was fearful because I didn't know what they were going to do to him the next time.
11	Travel is something we only dream about.
12	I never thought this type of back surgery could destroy a family.
13	I try to accept it and be strong and understanding.
14	I put extra stress on myself, as a result I had a heart attack.
15	I have become more self-sufficient.
16	We have not experienced some of the negative effects as we have good family support and religious background. We have been lucky.
17	We got professional help to save our marriage. We are okay now.
18	We all coped. He didn't dwell on it.
19	He very rarely took his frustrations out on the rest of us.
20	With medical and family support the physical pain is difficult but manageable.

had to do with illness in the partner, i.e., stress-related illness (6) and heart attack (15). Focus on the pain sufferer was indicated in Statement 1 "he suffered severe depression" and Statement 7 "my husband's self esteem is gone." Statements relating to relationships were 12 (back surgery destroys a family), #19 (he did not take his frustrations out on us),

and 4 (having to learn to trust people again). Severe partner-initiated marital disruption was indicated in Statement 2, ". . . I could not take anymore and divorced him." Statement 5 (I have to work two jobs to support the family) may fit in Cluster 1 (Depression/Isolation) or Cluster 5 (Countercoping). Statement 10 may relate to Cluster 1 as fear was mentioned. The financial concerns of Cluster 5 or the pain focus of Cluster 6 may be reflected in the statement, "travel is something we only dream about" (11). Finally, Statement 9 (not once did WCB or doctors involve me or even talk to me) may suggest isolation (Cluster 1) or lack of support (Cluster 5).

The introduction of additional statements did not seem to call for additional themes, however, some of the statements broadened existing categories or increased the specificity of category content. Additional coping and support strategies were added. Depression and self-esteem difficulties were identified in the pain sufferer. Deterioration of partner physical health and fear were added to intrapersonal effects.

Discussion

A unique and major contribution of this research is the rating of experiences described by participants which resulted in the following composite common description of the experience of living with a CLBP patient. When low back injury or trauma and resulting pain becomes chronic, the life of the sufferer and the lives of his partner and family are "turned upside down" and they all suffer the painful effects of chronic pain. The focus of the family shifts from its members and their development to the pain which has become an unwelcome intruder and a priority in their lives. The family seems to become suspended in the present, "put their lives on hold," "take one day at a time," and "find it difficult to look forward knowing the pain will always be there." It is a highly discomposing experience marked by "not knowing what to do." For spouses, the most commonly and strongly felt experience is frustration from inability to do anything about her partner patient's pain. She becomes consumed by his great need for attention and

encouragement and constant worry about his health. Sexually activity is disturbed and life, in general, become less fun. The situation leaves the family "financially drained." To add to the difficulties interactions with WCB adds stress on the whole family and leaves the couple feeling unsupported and angry. In response to these difficulties many spouses attempt "to live with pain and its effects," perhaps by "doing things differently." Most attempt to cope by recognizing that things could be worse. Many learn patience and compassion for others because of their experience of living with a CLBP sufferer.

This research substantiates the fact of emotional distress in the spouses of CLBP sufferers and contributes to a greater understanding of its nature. While fatigue, sleep disturbance, irritability, fear, and feelings of sadness and depression have been described (Kerns & Turk, 1984; Rowat & Knafl, 1985; Ahern & Follick, 1985; Flor, Turk & Scholz, 1987; Schwartz, Slater, Birchler & Atkinson, 1991) this research suggests that resentment, sorrow, frustration, worry, helplessness, guilt, anger, and bitterness can also be emotional components of this experience. Furthermore, spouses may bury these negative feelings to protect their CLBP partners. Feelings of being overwhelmed by the experienced were also expressed. Rowat and Knafl (1985) described aloneness, loss of freedom and sense of being separated from the patient. Similarly, aloneness, desire to withdraw from patient and feeling great responsibility are described in this research.

Physical response to chronic pain in a partner has been reported in the literature including, increases in blood pressure, migraine headaches, gastro-intestinal distress, and pain. This research did little to add information regarding physical impact on the spouse. What may be considered physical were subsumed as symptoms of depression i.e., fatigue and sleep disturbance. However, new additional statements mention stress-related illness and heart attack related to the CLBP experience.

Current literature reports high incidence of marital disruption, especially when the site of chronic pain is low back and/or the spouse is female (Ahern, Adams and Follick,

1985; Feinauer & Steele, 1992; Flor, Turk & Scholz, 1987; Kerns & Turk, 1984; Roy, 1985a, 1985b; Roy & Thomas, 1989; and Subramanian, 1991). Disruption is commonly attributed to sexual dysfunction, and disruption of roles and communication patterns. This research adds by specifying further sources of disruption, such as, a loss of dignity, trust and closeness in the marital relationship. The partner may experience loneliness and a sense of apprehensive unpredictability in relation to her partner. Such effects may contribute to relationship fatigue and eventually lead to thoughts of giving up and/or divorce. Four percent of participants indicated that the patient had left the marriage. No data indicate the rate at which spouses had left their CLBP partners.

Literature exploring the effects of chronic pain on marital relationships and effects of marital satisfaction on patient functioning is abundant. This research further describes couple functioning and depicts the disruption attributed to CLBP of a broader range of relationships. A dynamic similar to that described as an approach-avoidance paradigm (Schwartz, Slater et al., 1991) in which spouses are simultaneously drawn toward their suffering husbands and pushed away by their anger and hostility are described in this research. This research paints a picture of a partner potentially consumed by concern for the well-being of the CLBP sufferer with whom they live, on one hand; while on the other, the partner was the hapless recipient of the sufferer's rage and fear.

Relationships influenced by the experience of CLBP include those of the partner, children, nuclear family, extended family and friends. Statements connoted the persuasiveness and severity of impact on the family unit of living with a CLBP sufferer. Further, it seemed that the situation may lead to the breakdown of the couple and nuclear family unit. Finally, the deleterious impact of chronic pain extends outside the nuclear family to affect extended family and friends as well. Personal relationships, it seems, suffer in the presence of CLBP.

The research of Rowat and Knafl (1985) highlight a central theme of uncertainty arising from chronic pain. Uncertainty of the nature of pain, management of pain and family life and consequent feeling of loss of control of one's life is identified. Prominent in their research is "a sense of helplessness at being unable to affect any change in their mate's pain and uncertainty as to how to proceed" (p.264). Helplessness is likewise prominent in this research as is indicated in the statement most strongly and commonly endorsed (96%) was, "I was frustrated because I couldn't do anything about his pain." Likewise, 88% of the participants of this survey definitely agreed that "we did not know what to do." Rowat and Knafl (1985) found that uncertainty precluded the development of appropriate management strategies. The production of new behaviors to adapt to the changes brought by chronic pain and to obtain relief from its emotional consequences is very difficult because of the many uncertainties surrounding the experience.

To date research has focused on coping among chronically ill patients, chronic pain patients, and the coping of family members as it impacts the patient. This study adds to the literature by beginning to fill the void of understanding of coping among spouses of chronic pain patients. Eleven of the 70 statements suggest ways in which participants have attempted to cope with living with a CLBP patient. Six of the statements reflect emotion-focused coping—attempts to modify emotional functioning in the face of stressful events (Lazarus & Folkman, 1984). Passive forbearance (Pearlin & Schooler, 1978) probably designed to manage the stress of the situation is suggested in the statement, "I've learned to live with pain and its effects as a matter of necessity." Positive comparison (Pearlin & Schooler, 1978) as an attempt to control the meaning of CLBP is indicated in the statement, "I take comfort in that things could be worse." "I can't be understanding and supportive anymore," "I take on jobs or activities just to stay away from home," and "I feel like walking away," all seem to be methods of coping by distancing (Lazarus & Folkman, 1984) or avoidance (Cronkite & Moos, 1984). Finally, emotion-focused coping is evident in the statement, "I feel guilty for being angry," and

can be labeled self-blame (Lazarus & Folkman, 1984). It is possible as is suggested by Holohan and Moos (1987) that the use of these avoidant measures may lead to increased psychological distress in the long run. For this group, endorsement of coping by withdrawing ranged from 25% to 38%, and 58% indicated self-blame. The more functional passive forbearance and positive comparison were endorsed by 85% and 88%.

"I've learned to do things differently," "I deal with situations as they arise, one day at a time," and "I do more things alone now," are indicative of problem-solving coping, specifically by either attempting to modify the situation or developing self-reliance. What is outstanding about these statements is their high use by participants, 94%, 96% and 71% respectively. Another distinctive feature common among these statements is lack of specific problem-focused behavior which may serve to change the situation or eliminate the problem.

Seeking of social support is considered a mixed emotion- and problem-focused coping method. Support from the patient partner was indicated by 84%; support from family and friends, 48%; and support from WCB pain management course 11%.

While most events require a balance of emotion- and problem-focused coping strategies (Lazarus & Folkman, 1984) it seems that for this group there is a preference for emotion-focused methods of coping. The relative absence of proactive problem-focused coping may indicate that the event of chronic pain may not be amenable to active coping (Taylor & Aspinwall, 1993) or, may be attributed to ignorance of chronic pain on the part of the patient and partner. It seems logical that the implementation of active and/or problem-focused strategies would be difficult if individuals do not understand the problem at hand, as seems to be the case for this group of participants.

It is known that psychological and physical functioning of chronic pain patients is enhanced by positive self-statements, ignoring pain, activity, diverting attention (Jensen and Karoly, 1991; Keefe and Williams, 1990). Spouses who understand and encourage

these behaviors may facilitate coping in the patient. On the other hand, spouses who exhibit or encourage patients to fantasize, expresses emotion and blame themselves may experience a reduction of emotional adjustment and contribute to increase level of distress in the patient (Cronkite & Moos, 1984).

Similarly, spouses who understand, use and encourage the behaviors identified in Knish's (1994) Adaptive Coping Cluster may produce a positive effect on the patient. These include the use of positive thought, diverting attention from pain, positive comparison, accepting limitations (learning about the injury and pacing), understanding pain and accepting the injury.

Positive changes in the lives of individuals who experience chronic illness, i.e., cancer, have been identified (Collins et al, 1990). Similarly, for this group, the chronic pain experience seems to have taught 90% of spouses greater patience and compassion for others.

CHAPTER 5: SUMMARY AND CONCLUSIONS

The three-fold purpose of this study was to gain a fuller understanding of the experience of female spouses of chronic low back pain (CLBP) sufferers, to determine themes underlying this experience, and to determine which of these experiences were most common and prominent. Using concept mapping methods, this research provided a wealth of information about the experience of living with a CLBP sufferer. An important feature of the obtained data is its relative freedom from the constraints of predefined constructs and researcher bias. The participants described the phenomenon, established the underlying themes of the experience and confirmed the relevance of each experience. It is thus thought that this research is unique in its fullness of description of the domain of the experience of living with a CLBP sufferer, and in its integrity with the actual experiences and thoughts of participants. This chapter will summarize the results of the various phases of this research, present conclusions and implications, describe limitations and suggest further related research.

In Phase One, fourteen female spouses described their experience of living with a sufferer of CLBP. No two persons' stories were exactly the same, each contributed statements rendering a fresh perspective. In this way living with a CLBP sufferer is an experience unique to any given individual. The 70 statements of Table 2 and the additional statements of Table 6 portray the kinds of experiences an individual may have. Experiences range from extremely negative as in bitterness, desperation, turmoil, cruelty, fear of suicide, and divorce, to those experiences which suggest coping or growth, as in learning to live with pain or learning compassion. In general, however, the experience of living with a CLBP sufferer is predominantly negative.

While experiences may be unique to individuals or small groups of individuals, Phase Three of the research sought to determine which experiences were common and/or strongly endorsed. Of the 70 statements, 24 were either strongly endorsed or agreed to by

at least 75% of the 71 participants who responded to the rating questionnaire. A composite of these experiences provides the following picture of what may be considered "typical" or at least common for those living with a CLBP sufferer. The introduction of CLBP changes life dramatically for the whole family. As pain becomes the priority, the family becomes suspended in the present and all members of the family suffer. Spouses become consumed by the needs of the pain patient, at the same time, do not know what to do about their partner's pain. Spouses experience a reduction in quality of life (i.e. sexual, recreational, financial). Interactions with WCB adds additional stress and leaves the couple feeling unsupported and angry. Spouses attempt to adapt and cope and learn greater compassion for others. While the experience of living with a CLBP sufferer is generally negative, nine of the 71 participants indicated an intensely negative experience, and five seemed to have had an experience which was not at all negative. The differences in these groups may be a reflection of coping ability.

In Phase Two, 21 participants sorted the original 70 statements into groups that made sense to them. Concept mapping statistical and conceptual procedures applied to participants' sorts yielded seven clusters of conceptually similar statements. The seven clusters suggested underlying themes identified by participants and labeled by the researchers are: 1) Depression/Isolation, 2) Coping, 3) Severe Couple Disruption, 4) Focus on Pain Sufferer, 5) Countercoping, 6) Pain Focus, and 7) Relationship Disruption.

The picture painted by the statements in the Depression/Isolation cluster depicted the loneliness, isolation and emotional turmoil, especially depression, experienced by women living with CLBP sufferers. The fact that 18 statements are included in this cluster demonstrated the variety and breath of intrapersonal experience and highlighted the prominence of depression as a consequence of living with a chronic pain sufferer.

Coping was the only cluster with a positive bent. Statements in this cluster suggested that, for some, the experience of living with a CLBP sufferer could be a

learning experience whether neutral or positive. This cluster also reflected the use of coping strategies to obtain comfort or to deal with the uncertainty of chronic pain. Whereas other statements in the cluster were adaptive measures performed by participants, the gradual healing of pain could facilitate coping.

The statements of Severe Couple Disruption cluster reflected extremely negative changes in the marital relationship, even marital disruption. A loss of dignity and trust in the relationship, apprehensive unpredictability, loneliness from loss of closeness were indicated. Relationship distance may degenerate to relationship fatigue and eventually lead to thoughts of giving up.

The Focus on Pain Sufferer cluster described CLBP patient behavior which is either potentially harmful to the himself, or likely to impact the day to day life of his spouse. Overall, this cluster provides an account of a spouse potentially consumed by concern for the well-being of the CLBP sufferer with whom they live, on one hand; while on the other, the spouse was described as the hapless recipient of the sufferer's rage and fear.

The Countercoping Cluster had to do with the financial hardship of living with CLBP, an inability to get needed support, and deleterious treatment by WCB. The suitability of the label, Countercoping, is justified by the manner in which financial hardship, lack of support, and WCB conflict work against coping.

The meaning of the Pain Focus cluster can be summed up in the phrase, "Where we once had a life, we now have pain." The replacement of pain for normal life is suggested in the statements of this cluster.

The Relationship Disruption cluster indicates that relationships affected by the experience of CLBP include those of spouse, children, nuclear family, extended family and friends. Statements connoted the persuasiveness and severity of impact on the family

unit of living with a CLBP sufferer. Further, it seemed that the situation may lead to the breakdown of the couple and nuclear family unit.

The map was vertically partitioned into two regions. The left side of the map, seemed to represent factors which either caused (Pain Focus Cluster), exacerbated (Countercoping Cluster) or remediated (Coping) the problems related to living with a chronic pain sufferer. The right side of the map appeared to be composed of clusters indicative of the consequences of the Pain Focus and related unsuccessful resolution of the struggle between Coping and Countercoping. The consequences depicted on the right side of the map were either intrapersonal or interpersonal. Intrapersonal effects were largely related to depression with its accompanying symptomotology and secondarily to isolation and loneliness. The interpersonal product of pain included disruption of a number of relationships (i.e., couple, child, nuclear family, extended family and friends) and the expense of concern and focus by the partner for the chronic pain sufferer.

Conclusions

Living with a CLBP sufferer is a predominately negative experience with which all are forced to cope. The primary effect of CLBP is the radical change it introduces in the lives of CLBP sufferers and their spouses. Normal life disappears and pain becomes a priority in all aspects of daily living. It not only dominates the present but clouds the future. In response to this upheaval a large majority of spouses institute a variety of adaptive and coping measures. Unfortunately, for most, a number of factors compound the problem of pain, potentially undermining ability to cope. Financial difficulties and stressful interactions with WCB are important countercoping factors but most significant is uncertainty and related sense of helplessness.

CLBP and the interplay of coping and countercoping result in deleterious intra and interpersonal consequences for spouses. The most severe repercussion was intrapersonal, largely related to depression and related symptomotology and secondarily

to isolation and loneliness. Similarly consequential was the interpersonal product of pain which included disruption of a number or relationships: couple, nuclear family, extended family and friends. Pain is a key figure in these disruptions. More severe behavioral and emotional factors contributing to couple disruption are not as widely or intensely experienced, however are felt by approximately one-third.

It can also be concluded that the experience of living with a CLBP sufferer is not an invariable experience across individuals or is it managed equally as successfully by all spouses. While the majority's experience was generally negative, 12% were highly distressed and 5% were not distressed. A form of the questionnaire may be used to determine level of distress. Such a protocol may also be used to guide decisions regarding need for and form of treatment for spouses.

Several conclusions can be drawn regarding the nature of treatment based on this research. First, CLBP is a family affair, in that all the sufferer's relationships are affected, which calls for mutual supportiveness, and requires knowledge of chronic pain by all parties. Second, the primary foci of treatment applicable to almost all spouses would be: 1) the retention of as normal a life as possible, despite the presence of pain, and 2) the reduction of uncertainty about the nature of chronic pain and what to do about it. A third objective is the broadening of coping repertoire including enlarging emotion-focused and proactive problem-focused strategies. Fourth, while provision of adequate financial and physical support may do much to counter stress, a more reasonable objective may be improved financial and time management. A fifth objective may be the encouragement and facilitation of support-seeking behaviors. Sixth, the facilitation of successful interaction with WCB would reduce stress. A seventh treatment focus could be sex education specific to adapting to CLBP. Finally, the institution of a support group for spouses would allow for the sharing of experience and act as an outlet for expression of otherwise bottled-up thoughts and feelings.

A smaller group of spouses, those identified as suffering from depression, may receive more intensive individual and/or group psychotherapy. In the case of spouses who experience greater couple disruption and/or focus on the pain sufferer, couple therapy may be indicated. For this more severely impacted group, the poor functioning of the patient is likely to contribute to the indisposition of the spouse. This research suggests that such poor functioning CLBP patients and concomitantly spouses and family members would benefit from development in pain management, emotion management and coping. Finally, increases in emotional, psychological, and physical self-sufficiency of patients would benefit a large majority of spouses.

The WCB Rehabilitation Center is a division of the Board and is mandated to provide rehabilitation services to individuals who have been injured on the job and to their families. Indeed, it seems that workers and their families may look to WCB for help and support. Almost three-quarters of spouses would like to be involved in their partners' pain treatment, but only approximately 30% have been included. Seven percent or less of spouses have received support and treatment for issues related to living with a CLBP sufferer. It seems that for this group, WCB has neither utilized spouses to facilitate treatment of patients or provided treatment for spouses for their own benefit. Unfortunately, some may find interactions with WCB to be less than rehabilitative. In fact, WCB is commonly experienced as judgmental and is implicated in an exacerbation of problems by adding undue stress on the family.

It appears that most of the patients who attended the Rehabilitation Center from 1990 to 1995 and whose spouses responded to this research had not participated in the formal pain management clinic. However, it appears that positive experiences for the spouses can be attributed to the Pain Management Program at the Rehabilitation Center. It is concluded that patients and their spouses would benefit from improved interaction with WCB and inclusion in a formal pain management clinic.

In general, this research suggests that most female spouses of CLBP sufferers are significantly negatively impacted by CLBP of the patient. It also provides a rich description of the experience, identifies experiences which are most relevant to the majority of spouses and distinguishes themes for this experience. It also confirms the long-established need for treatment of spouses, provides guidelines for such treatment and introduces a precursory tool to guide inclusion in treatment and prescribe treatment foci.

Limitations

Since the purpose of this study was exploratory in nature, findings are considered preliminary and any interpretations must be made with the following limitations in mind. The participants for this study were female spouses of CLBP patients who had received compensation from the Workers' Compensation Board of Alberta. Additionally, patients had received some level of service from the WCB Rehabilitation Center. As was clearly indicated by the results of this research, WCB is a significant component of the experience of participants. Results may not generalize to other groups, especially those that do not have coinciding institutional involvement, particularly institutions which function in multiple roles as does WCB.

Participants of this research were all female spouses of CLBP patients. Earlier research suggests that gender is a relevant determinant of the kinds of experiences an individual is likely to have (i. e., less severe for male spouses). While inclusion of only female spouses adds clarity to an exploration of this group's experience, some important experiences relative to the experience of living with a CLBP female may be excluded. Also, generalizability to other chronic pain anatomical sites and syndromes may be limited. There is some suggestion, for instance, that the impact of CLBP is more severe than for other chronic pain syndromes.

Employment and socioeconomic data are not available for the participants of this study, however it is generally thought that WCB clients have lower socioeconomic status. Compared to other female spouses of CLBP sufferers, this group may have fewer available resources and consequently experience greater negative impact when confronted with significant challenges.

The response rate for this study which was relatively low (20% for the Rating Survey) may be a factor affecting the data in some way. It is difficult to know what contributed to this rate of return, however a distrust of WCB is one likely deterrent to responding. Regardless, it is necessary to interpret results with caution.

Because research questionnaires were mailed to the addresses of patient's, spouses who were no longer living with their partners may have been less likely to respond. This may result in an underestimate of marital breakdown and/or omit the perspective of spouses with more severe experience, less ability to cope, greater alternative resources, or who differered in some other way compared to spouses who responded.

Participants of the Rating Survey identified an additional 20 experiences that had not been included in the concept mapping or rating survey analysis. This indicates that the list of experiences in this study may not be entirely reflective of the domain of experience of living with a CLBP patient.

Further Research

The findings of this study have implications for further research. Additional studies are indicated to validate the results of this investigation and explore reliability. A series of comparative studies may be undertaken to contrast these results with concept maps of the experience among other chronic pain syndromes, nonWCB spouses, nonWCB patients, and male CLBP spouses.

The response rate of future studies may be improved using other data gathering procedures, i.e., live telephone interviews. Further studies may also query a larger

number of demographic variables, such as, socioeconomic level, employment, and desire for treatment.

Additional research may look at specific factors and variables which account for the differential effects of CLBP for high-distress and low-distress groups of spouses. Also suggested are controlled studies of impact of CLBP and treatment effectiveness when countercoping factors are reduced or eliminated. A concept mapping study may look specifically at coping with living with a CLBP patient. Such coping research should not rely on traditional measures of coping alone (i.e., biochemical functioning, return to prestress activity and reductions in psychological distress) but include measures of quality of life.

The inclusion of the additional statements gathered from the Rating Survey and further statement generation could result in the compilation of a comprehensive portrayal of the experience of living with a CLBP patient. This list of statements may then be subjected to the concept mapping process thereby capturing the domain of experience. Comparisons among different groups of sorters may also be made (i.e., spouses vs. patients vs. professionals).

Such a comprehensive statement list may be used to develop a psychometrically sound instrument that could be used to monitor the overall impact on the spouse, identify which areas of impact are most affected, evaluate the presence and impact of coping or countercoping variables, and monitor levels of pain focus. This could be used to evaluate the effectiveness of treatment, identify high-risk spouses, and be used as a guide for treatment planning.

In general there is a need for research evaluating the effectiveness and nature of including the spouse and/or family in treatment for their own benefit. Treatments might appropriately be multitheoretical and based on empirically derived methods targeting specifically determined problems.

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APPENDIX A

Phase One Cover Letter

The Experience of Partners of Male Chronic Low Back Pain Patients

Dear Participant:

We are conducting a study to learn more about what it is like for women who are married to individuals with chronic low back pain. We would like your help with this study. Your participation is strictly voluntary and all information will be confidential. Your being in this study will not affect your partner's relationship with WCB, including WCB claims and treatment. You may withdraw from the study at anytime at no consequence to you. Sending in your completed forms will mean that you agree to be in the study.

This package contains a questionnaire, demographic information page, and instructions. We would like you to write statements that tell us what it is, or was, like for you to have a partner in chronic pain. It should take you about 10 minutes. It is hoped that the results of this study will help in the development of effective support services for partners of chronic low back pain sufferers.

If you agree to participate in this study, please complete the enclosed questionnaire and demographic sheet and return them in the enclosed stamped, self-addressed envelope. If you have any questions or concerns or would like a copy of the results of this study please feel free to contact Dr. Peter Calder at 492-3696.

Return of this questionnaire within 10 days will be greatly appreciated.

Thank you for you time and cooperation.

Dr. Steve Knish	Dr. Peter Calder
Psychologist	Professor
Workers' Compensation Board	

APPENDIX B

Phase One Demographic Survey

THE EXPERIENCE OF PARTNERS OF MALE CHRONIC LOW BACK PAIN PATIENTS

Dear Participant,

Thank you for taking the time to volunteer for this study. Please complete the demographic information below.

DEMOGRAPHIC INFORMATION

1. Age :_____
2. Length of time you have been living with your partner_____
3. Number of children living at home_____
4. Length of time your partner has been in pain_____
5. How long has your partner been treated for chronic low back pain?_____
6. Have you ever been involved in your partner's pain treatment? Yes No
7. Would you like to be involved in your partner's pain treatment? Yes No

Please return this form with your list of statements.

APPENDIX C

Phase One Questionnaire

THE EXPERIENCE OF PARTNERS OF MALE CHRONIC LOW BACK PAIN PATIENTS

Partner's Statements

We are conducting a study about the experience of women who have partners with chronic low back pain. It is hoped that a compilation of statements from a number of women will provide a clear understanding of the experience and aid in the development of treatment programs for the partners of chronic low back pain sufferers.

Completion and submission of this form will be taken as your consent to participate in this study.

Please respond with written statements to the following question:

"What is/was it like for you to have a partner in chronic low back pain?

1._____

_____

2._____

_____

3._____

_____

4._____

_____

5._____

_____

6._____

_____

Page 2 Partners' Statements Questionnaire

7._____

_____

8._____

_____

9._____

_____

10._____

_____

(Please use the back of these sheets if you need more space to respond)

Thank you for taking the time to respond.

Your statements will form an important part of this study.

After we collect the statements of several women, we will compile a master list of statements. We will then send a package of cards with the statements on them to women who volunteer, to sort into categories. Once the statements are sorted, the information will be analyzed so that we can determine the common experiences of women with partners with chronic low back pain.

If you are willing to help in the next part of this study by sorting statements into categories, please fill in your name below. Sorting should take about 30 minutes.

I am willing to be involved in sorting the statements into categories: __**Yes**__**No** (check)
If yes, please provide your name, address and phone number where you can be reached and return in the self-addressed envelope to Dr. Calder.

Name_____ Phone_____

Address_____

_____Postal Code_____

Thank you again for your time and help!

APPENDIX D

Phase One Statement Transcription

Statements First Draft

1.1 Frustrating-knowing he was in pain and I couldn't do anything about it.

1.2 Lonely-we stopped seeing all our friends because of the pity we saw in their faces.

1.3 Sad-our lives were turned upside down. Did not know what to do.

1.4 Financially draining-no money to go out and have fun.

1.5 Embarrassing-having to watch my husband crawl from point A-B.

1.6 Lost trust- he'd steal pills for his pain, he took 16-20 extra pills a day. They no longer worked.

1.7 Maddening- not knowing if it would ever get any better.

1.8 Angry-no one knew what to do to help us.

2.1 The pain is of a priority consideration in all aspects of our daily living.

2.2 Because of the foregoing, there are many times I find I am resentful of it.

2.3 I feel a sadness for the many fun things we no longer share i.e. dancing, curling etc.

2.4 It has curtailed our social life and building of a circle of friends.

2.5 Our life has been very little "fun" to it as my husband's pain is reflected outwardly.

2.6 It is difficult to look forward with anticipation when you know the pain will always be there.

2.7 Resentment and sorrow make up a good portion of my life which is not the way one would wish to live.

3.1 Anger- Pat very often will still wake up angry. Our innocent children and I have become victims of (at times like these Pat not able to cope with his pain) verbal anger and impatience which leads at times to physical release. I see this as a need to be in control of "something" being as he cannot change or control his situation.

3.2 Depression-Pat's self-maintenance, bathing, hair cuts, clean clothes has been a big issue-very neglected- He has needed much attention or encouragement from me. Depression, after the 3rd surgery not helping the pain problem, became a major! concern. Pat received medication for depression, This did not help on its own. I encouraged counseling and life skills teaching. The support from the Pain Management Course (WCB) offered the beginnings of the ability for Pat to recognize the need for learning about himself. This was only a mere beginning which strengthened me also. Thank you! WCB for this. We pleased for (from our hearts) for further help. We were offered 10 sessions of a psychologists time, now 10 more. Out pain is healing even though Pat's is still there.

3.3 Denial-Pat still, unrecognizingly! pushes his physical limitations to try to be "like he was". Andrew would outright deny doing things he has cone that made him over tired. He was never really instructed to care for himself. I feel concerned about this!

3.4 Loss of self-esteem-feelings of not being "whole" because Pat can now only be with the children and pay the bills as in do the banking, buy the groceries and do some cooking with is not where his past strengths were.

3.5 Want of isolation-withdrawal from socialization. We are not like other people!?

3.6 Fears-escalate as the pain has not improved from surgery #1 to surgery #3. Why have another surgery even though a fusion has not healed?

3.7 Frustration became an issue as others-his family and most friends could not show compassion for Pat.

3.8 Our love making has been challenged by the sadness brought from not being able to be free to do as one feels as the time e.g.. concern due to position, absence at times of the ultimate climax, Verbalizing, sharing and touch are wonderful comforts for both.

3.9 I've left space #9 to the last as I wanted to say something positive has come from our troubles. From my very weak times, I've learned to be patient and sharing with compassion for others, most to all for Pat. Also, I've tried to teach our children patience and love and understanding for our situation. I do need help with this process though.

3.10 Above all- the factual, actual constant cruel pain is a reality which takes away from Pat's, Fred and Roy's and my lives.

4.1 I always have to rub his back.

4.2 Can't do the things he used to do so he starts to feel guilty and depressed. So I have to cheer him up.

4.3 After awhile you start to worry about him all the time.

4.4 I do all the heavy lifting and work and I get tired easily more now.

4.5 Sleeping with him was an experience in itself his back would start having a spasm and he thinks mice are crawling up his back so he jumps up and strips the bed.

4.6 He always thinks you are going to leave him because he can't do the things that he used to.

4.7 His family and friends stop asking for help.

4.8 We can't go shopping together for very long because certain floors are harder on his back.

4.9 Every morning his back hurts and he can hardly get out of bed.

4.10 His bones are always cracking or popping when he moves. After awhile you start to treat him like a child just to make sure he doesn't get hurt. But then you have to learn to trust him all over again. To trust him to make sure he knows his limits. It put a great stress on the marriage. It becomes hare to have sex because I think it could hurt his back. After his surgery his legs still have loss of feeling. There is so much the woman does that nobody realizes that there wouldn't be enough paper to write it all out.

5.1 I do many things alone, because of this physical limitations (i.e. bowling, slow pitch, power walking)

5.2 I hate feeling helpless- I want to be able to help relieve his pain, but cannot do anything about it.

5.3 Medication has diminished sexual drive-when we do partake he sometimes for it later.

5.4 It bothers me (sometimes) that I have to get up for work everyday and doesn't (then I feel guilty about feeling that way) because I know Pt would rather be working.

5.5 His disposition has changed dramatically since his injury-he used to be easy going and fun-he is not bitter toward just about everything (I think its a mild depression).

5.6 I worry about him mixing medication with alcohol. Alcohol seems to relieve his pain more effectively than med.

5.7 I feel that since his injury our life has been put on hold, especially financially.

5.8 It bothers me greatly not to know what the future holds in relation to Pat's back (will another operation help?-the first two only made his condition progressively worse)

5.9 We argue more than we every did before his injury.

5.10 I worry about his general health-the effects of prolonged medication, addiction, organ damage, trouble sleeping etc.

6.1 Not as exciting as having an amusement park in your backyard.

6.2 The emotions and pressure that the children go through is not very comfortable for either party. My husband's pain was so bad in June. My son goes to Catholic school every morning he would make sure that they would pray for his dad to get better. His marks in school dropped, He just didn't want to be there so we had to take him out.

6.3 My emotions and frustrations are bottled up inside me. One day I can talk and bring those frustrations out but right now they are the least of our worries.

6.4 The future is our biggest worry also. How can we deal with this especially with only one of us with one income and not money for support. Even if there was a chronic pain clinic nearby that was affordable maybe.

7.1 It makes a person very helpless to be unable to relieve pain.

7.2 Even though I'm from a health professional background I was not able to help solve the pain and so feel inadequate.

7.3 Dealing with WCB placed undue stress upon the whole family. They certainly make you feel like a liar and unworthy of their service.

7.4 We've had to relearn to do some things, or at least do them in a different way.

7.5 Even though one tries very hard to be understanding it is difficult not be defensive and angry.

7.6 The back injury placed financial strain on our family which in turn creates a disruptive force.

7.7 I felt as though we were being judged at the WCB appeal hearing.

7.8 Our expectations have been forced to change with regards to activities, financial outcomes, goals and expectations.

7.9 Some days his life is/was Hell. Even though he tried hard to control his pain/anger it still surfaced.

7.10 The side effects of the low back pain on the family were/and sometimes still are, as gnawing and painful and uncomfortable as the pain itself.

7.11 We have felt defeated-as there are still no real answers or solutions for the pain.

7.12 We have learned to live with the pain and effects of it, as a matter of necessity. Medication does not play a part in pain control. Lastly WCB has been demoralizing. Decisions regarding human life are made by people who have not every laid eyes on the client much less seen the effects of the client/client's family. Because of severe allergic reaction to anti-inflammatory medication and pain killer, we have had to make extra efforts to find other solutions for dealing with pain. This was done without the support of WCB. One thing is for sure, and that is that we deal with situations as they arise, take one day at a time, and appreciate what we have today. If one takes the time to look around there is always someone is a worse predicament.

8.1 Very frustrating there is nothing I can do to help.

8.2 There are tremendous feelings of anger and guilt for feeling angry.

8.3 It is very difficult-all responsibility has fallen on my shoulders.

8.4 "Peaceful" communication is almost non-existent.

8.5 Its very lonely, we now avoid each other.

8.6 "Sharing" has become "selfishness".

8.7 Its like being with a stranger who has become a miserable child.

8.8 You walk on eggshells, never knowing what to expect.

8.9 My personal feelings have to be put on hold until I know what kind of day he's having.

8.10 Very unstable and full of turmoil.

8.11 I feel I could write a whole book on what it is like to live with someone which chronic pain. I think a support group is a great idea-well needed. We have attempted marriage counseling, but it wasn't every effective. Out therapist was very perceptive; however, most time was spent on dealing with chronic pain, not on the problems it has created in our relationship. We know we need help, but neither of us can find the assistance we need. I have tired to be understanding and supportive but I just can't do it anymore. It may sound selfish, but when is it my turn!?

9.1 Trying desperately to handle severe depression in my partner's life and my myself also.

9.2 Afraid to leave my partner alone in case his threat of suicide would become a fact.

9.3 Total loss of any social life, as severe pain has made it difficult to cope with his sitting for long.

9.4 Loss of extra income, severe stress from extra worries by difficulties with WCB.

9.5 Not being aware of what I could do to help more than I have, feeling helpless.

9.6 Feeling all alone never having anyone to turn to, lonely, tired, wanting so badly for some support.

9.7 Because of my husband's severe pain our love and sexual relationship has severely suffered.

9.8 "Wondering, if" it is possible for my partner to become involved in some program, studies, or hobbies so that he will once again feel a sense of accomplishment instead of this deep sense of loss he feels each day. Because of

such severe pain he feels worthless, and I am at a loss in how to better help him, each day becomes a continued burden.

10.1 My work load now has tripled and with the amount of pain he has in his back I don't see any foreseeable relief in the future.

10.2 My sleep pattern is much disturbed as my husband will be up all hours of the night, as his back bothers him and he can't sleep more than two hours at a time.

10.3 I now have to do all the shopping myself, he can't walk that far anymore.

10.4 We now never go to dances, he tried to go and do some slow dances and the next morning about 4 am he ended up taking about five 292 to control the pain plays anti-inflammatory pills.

10.5 We can't go to movies anymore as he can't sit that long in one position.

10.6 When my husband hit 65 he was just about completely cur off by WCB. So now we don't have enough money anymore.

11.2 Trying to understand his pain, mood swings, his pride taken away, depression and anxiety.

11.3 I went into depression as well, on Prozac.

11.4 Not having a support group for my husband or myself.

11.5 Knowing that WCB is not in business to help the patient (worker). To us they have made out life as miserable as they could.

11.7 Telling your children there is not enough money to buy the necessities like bread and milk.

11.10 Our family have managed to stay together but alot of them don't.

12.1 Does not get involved with the children as much as he used to.

12.2 When he is in pain, everyone else is in pain an suffers.

12.3 He does not smile or laugh like he used to.

12.4 My husband is constantly yelling and screaming.

12.5 His loudness creates my constant headaches and sleepless nights.

12.6 I take on more jobs or activities just to stay away from home.

12.7 I took forward to Mondays and dread the arrival of Friday.

12.8 He is unable to do repairs or indoor and outdoor upkeep.

12.9 Life is pure hell living with someone with chronic back pain, especially men.

12.10 I think their would be a slight easement if he was not made to work while he is in pain cause he brings the pain home with him every day.

13.2 My husband continued to work even though he was in extreme pain, but was taking lots of medication. He went to physio 3 or 4 times a week and continued on medication, the medication made him very lethargic so all he did was work and sleep. It was very hard for me and the children to understand why my husband and father was acting that way and as months turned into years and my husband became unable to work he withdrew from us even more and because there was no support system or anyone to help all of us to understand, silence filled out home. WCB cut off my husband financially with no where to turn. He still in is considerable pain is now working again but he has left us. Was it, is it because of the pain, that he doesn't know what to do. I believe so.

14.2 He is always complaining about the pain.

14.5 It seems as the years go by he is getting worse and worse.

14.6 The worse the pain gets the least the doctors or WCB or anyone will help.

14.7 My sons have grown up with a father who can't do much with them.

14.8 He is spending too much time eating and is getting overweight.

14.12 People, Drs. and professional have no idea of the pain he is in and seem to poo-poo it thinking, oh it is just back trouble, but the pain is in his whole body and is constant and ever present.

14.13 I find myself fed-up with the whole situation, at times.

14.14 It is frustrating, irritating and times I feel like walking away.

14.15 At a time in our life when it should be getting easier it is financially harder. It is like starting at the beginning with nothing, only now we are retiring with nothing.

14.16 I feel angry at the system.

14.17 He was injured on the job, loved his job, would have given his life for his job and actually has-yet the system seems to have let him down. He hasn't gotten better so they are blaming him for not betting better.

APPENDIX E

Phase One Statements First Edit

No.	Statement
1	Frustrating knowing he was in pain and I couldn't do anything about it.
2	Lonely-we stopped seeing all our friends
3	Sad-our lives were turned upside down
4	We did not know what to do
5	Financially draining
6	No money to go out and have fun
7	Embarrassing having to watch my husband crawl from point A to B
8	Lost trust-he'd steal pills for his pain
9	Maddening, not knowing if it would every get any better
10	The pain is of priority in all aspects of our daily living
11	At times, I am resentful of the pain
12	I feel sadness for the many fun things we no longer share
13	It is difficult to look forward when you know the pain will always be there
14	Resentment and sorrow make up a good portion of my life.
15	Our innocent children and I have become victims of his verbal anger, impatience and physical release.
16	He has needed much attention and encouragement from me
17	Support from the WCB pain management course strengthened me
18	Our pain is healing even though Pat's is still there.
19	I feel concerned that Pat denies his physical limitations
20	Loss of self-esteem, feelings of not being whole
21	We are not like other people.
22	Want of isolation
23	Fears escalate as pain has not improved with surgery.
24	Friends and family could not show compassion for Pat.
25	Our love making has been challenged.
26	Verbalizing, sharing and touch are wonderful comforts for both
27	I've learned to be patient and sharing with compassion for others, especially Pat.
28	I need help to teach our children patience and understanding for our situation

29	Above all, the factual, actual constant cruel pain is a reality which takes away from every member of our family.
30	I always have to rub his back
31	I have to cheer him up
32	After while you start to worry about him all the time
33	I get tired easily more now
34	Sleeping with him is an experience in itself
35	He always thinks you are going to leave him
36	His family and friends stop asking for help
37	We can't go shopping together anymore
38	After while you start to treat him like a child
39	It put a great stress on the marriage
40	I do many things alone
41	I want to be able to relieve his pain, but can't do anything about it
42	It bothers me that I have to get up and go to work and he doesn't
43	I feel guilty for being angry that I have to go to work
44	He used to be easy going and fun, he is now bitter about just about everything
45	I worry about him mixing alcohol with medication
46	I feel that since his injury our life has been put on hold
47	It bothers not to know what the future holds
48	We argue more than we ever did before
49	I worry about his general health
50	The emotions and pressure that the children go through is uncomfortable
51	My emotions and frustrations are bottled up inside me
52	I am not able to solve the pain so I feel inadequate
53	Dealing with WCB put undue stress upon the whole family
54	We've had to learn to do things in a different way.
55	Although I try to understand it is difficult not be defensive and angry
56	I felt as though we were being judged by WCB
57	Our expectations have changed with regard to finances, activities and goals.
58	Even though he tried hard to control his pain/anger it still surfaced.
59	The side effects of low back pain on the family is as gnawing and painful as the pain itself
60	We have felt defeated as there are no answers or solutions to pain.

61	We have learned to live with pain and effects of it as a matter of necessity.
62	We deal with situations as they arise, take one day at a time, and appreciate what we have today.
63	If one looks around there is always someone in a worse predicament.
64	It is very difficult-all the responsibility has fallen on my shoulders
65	Its very lonely, we now avoid each other.
66	Very frustrating there is nothing I can do to help
67	There are tremendous feelings of anger and guilt for feeling angry
68	Sharing has become selfishness
69	Its like being with a stranger who has become a miserable child
70	You walk on eggshells, never knowing what to expect
71	My personal feelings have to be a put on hold until I know what kind of a day he is having.
72	Very unstable and full of turmoil
73	We know we need help, but neither of us can find the assistance we need.
74	I've tried to be understanding and supportive, but I just can't do it anymore.
75	Trying desperately to handle severe depression
76	Afraid to leave my partner alone in case of suicide
77	Total loss of social life.
78	Feeling all alone, never having anyone to turn to, wanting so badly for some support.
79	My sleep pattern is much disturbed.
80	Trying to understand his pain, mood swings, his pride taken away, depression and anxiety.
81	Telling out children there is not enough money for bread and milk.
82	Does not get involved with the children as much as he used to.
83	When he is in pain, everyone is in pain and suffers.
84	He does not smile or laugh like he used to.
85	My husband is constantly yelling and screaming
86	His loudness creates my constant headaches and sleepless nights.
87	I take on jobs or activities just to stay way from home
88	It was very hard for me and the children to understand why he was acting this way.
89	He withdrew from us even more because there was no support system.

90	Because there was no support system or anyone to help all of us, silence filled our home.
91	He is now working again but he has left us.
92	He is always complaining about the pain.
93	It seems as the years go by he is getting worse and worse
94	The worse the pain gets the less the doctors or WCB or anyone will help
95	My sons have grown up with a father who can't do much with them.
96	He is spending too much time eating and is getting overweight
97	I find myself fed-up with the whole situation, at times.
98	It is frustrating, irritating and times I feel like walking away.
99	I feel angry at the system.
100	He hasn't gotten better so they are blaming him for not getting better.

APPENDIX F

Phase Two Cover Letter

The Experience of Partners of Male Chronic Low Back Pain Patients

Dear Participant:

Thank you for volunteering to participate in the second part of our study to learn more about what it is like for women who have partners with chronic low back pain. Your participation is strictly voluntary and all information will be confidential. Your being in this study will, in no way, affect your partner's relationship with WCB, including claims and treatment. You may withdraw from the study at any time with no consequence to you or your partner.

The enclosed package contains 70 descriptive statements and recording sheets. The statements are those made women in an earlier part of this research. We would like you to sort the statements into categories that make sense to you. This task requires about 30 minutes to complete.

A stamped, self-addressed envelope is enclosed in the package so that you can return your completed recording sheets.

If you have any questions or concerns or if you would like a copy of the results, please feel free to contact Dr. Peter Calder at 492-3696.

Thank you for you time and cooperation.

Return of completed forms within 10 days would be greatly appreciated!

Dr. Steve Knish	Dr. Peter Calder
Psychologist	Professor
Workers Compensation Board	

HOW TO SORT THE STATEMENTS INTO CATEGORIES:

a) Read through the 70 statements.

b) Sort the statements into groups that have a common idea or theme in a way that makes sense to you. (You can create as many groups as you like from 2 and up within the following guidelines:

1. Do not put every card in its own pile
2. Do not put all the cards in one pile
3. Do not put cards in a miscellaneous pile

c) Once you have created your groupings of statements, write the statement numbers for each group on the attached score sheet and give the group a label.

NOTE: THERE ARE NO RIGHT OR WRONG GROUPINGS

APPENDIX G

Phase Two Demographic Survey

THE EXPERIENCE OF SPOUSES OF CHRONIC LOW BACK PAIN PATIENTS

Dear Participant,

Thank you for taking the time to volunteer for this study. Please complete the demographic information below. Information you provide will not be linked with your name.

DEMOGRAPHIC SURVEY

1. Age :_____
2. Length of time you have been living with your partner_____
3. Number of children living at home_____
4. Length of time your partner has been in pain_____(MONTHS)
5. How long has your partner been treated for chronic low back pain?_____
6. Have you ever been involved in your partner's pain treatment? Yes No
7. Would you like to be involved in your partner's pain treatment? Yes No
8. Have you participated in psychological treatment or a support group related to your partner's chronic low back pain? Yes No
9. Rate your impression of your partner's pain on a sale of 1-10 with 10 being most severe. 1 2 3 4 5 6 7 8 9 10

Please return this form with your card sort tabulation sheets.

APPENDIX H

Phase Two Sort Recording Sheet

EXPERIENCE OF PARTNERS OF MALE CHRONIC LOW BACK PAIN PATIENTS

STATEMENT SORT RECORDING SHEET PAGE ONE

GROUP	STATEMENTS	TITLE/LABEL
Example: 1	3, 17, 67,33,8.....	Reading is fun

(Please turn this page over and continue as needed)

STATEMENT SORT RECORDING SHEET PAGE TWO

GROUP	STATEMENTS	TITLE/LABEL

The final part of this study requires discussing the results of all parts of this study with a few women so we can see if the results of this study make sense.

Check if you are willing to be involved in an interview with the researchers: **__Yes___No**

If yes, please provide your name and the phone number where you can be reached and return in the self-addressed envelope.

Name_____ Phone_____

APPENDIX I

Phase Three Cover Letter

The Experience of Partners of Male Chronic Low Back Pain Patients

Dear Participant:

With the assistance of the University of Alberta, the Worker's Compensation Board of Alberta is conducting a study to learn more about what it is like for women who have partners with chronic low back pain. We would like your help with this study. Your participation is strictly voluntary and all information will be confidential. Your participation in this study will, in no way, affect your partner's relationship with the WCB, including WCB claims and treatment. You may withdraw from the study at any time with no consequence to you or your partner.

This package contains a questionnaire and brief demographic survey. The 70 statements on the questionnaire were written by several woman who answered the question, "What is /was it like for you to have a partner with chronic low back pain?" We would like you to rate each statement so that we will know if you agree with what is described in the statement. This should take you about 15 minutes. Remember, there are no right or wrong answers. We want to know if you experience what is described in the statements.

It is hoped that the results of this study will help in the development of effective support services for partners of chronic low back pain sufferers.

If you agree to participate in this study, please complete and return the enclosed questionnaire and demographic survey. If you have any questions or concerns or if you would like a copy of the results of this study, please feel free to contact Dr. Peter Calder at 492-3696.

Return of this questionnaire within 10 days would be greatly appreciated.

Thank you for your time and cooperation!

Dr. Steve Knish	Dr. Peter Calder
Psychologist	Professor
Workers Compensation Board	

How to complete the attached questionnaire:

a) Circle a number from 1-5 which shows how much you agree with each statement.

b) If the statement does not apply, circle NA.

Use the following scale:

1	2	3	4	5	NA
strongly disagree	disagree	slightly agree	moderately agree	strongly agree	not apply

Please Assign A Rating to Every Statement

APPENDIX J

Phase Three Demographic Survey

1. Age :_____
2. Length of time you have been living with your partner_____
3. Number of children living at home_____
4. Length of time your partner has been in pain_____(MONTHS)
5. How long has your partner been treated for chronic low back pain?_____
6. Have you ever been involved in your partner's pain treatment? Yes No
7. Would you like to be involved in your partner's pain treatment? Yes No
8. Have you participated in psychological treatment or a support group related to your partner's chronic low back pain? Yes No
9. Rate your impression of your partner's pain on a sale of 1-10 with 10 being most severe. 1 2 3 4 5 6 7 8 9 10

10. Your experience of what is/was like to live with a partner in chronic low back pain may not be described by the 70 statements of the attached questionnaire. Please write any new statements here.

_____

_____

_____

_____

_____

The next part of this study requires that the statements be sorted into categories. If you are willing to participate in the next part of this study please fill in your name below. Sorting should take about 30 minutes.

I am willing to be involved in the next part of this study: ____**Yes**_____**No** (check)

If yes, please provide your name, and an address and phone number where you can be reached and return in the enclosed self-addressed envelope to Dr. Calder.

Name_____ Phone_____

Address_____

_____Postal Code_____

Thank you again for your time and help!

APPENDIX K

Phase Three Questionnaire

The Experience of Partners of Chronic Low Back Pain Patients Questionnaire

1.	I was frustrated because I couldn't do anything about his pain.	1 2 3 4 5 NA
2.	I became lonely when we stopped seeing all our friends.	1 2 3 4 5 NA
3.	I was sad because our lives were turned upside down.	1 2 3 4 5 NA
4.	We did not know what to do.	1 2 3 4 5 NA
5.	The situation drained us financially.	1 2 3 4 5 NA
6.	We had no money to have fun.	1 2 3 4 5 NA
7.	I am embarrassed to watch my husband crawl from point A to B.	1 2 3 4 5 NA
8.	I lost trust in him when he'd steal pain pills.	1 2 3 4 5 NA
9.	The pain is of priority in all aspects of our daily living.	1 2 3 4 5 NA
10.	It is difficult to look forward knowing the pain will always be there.	1 2 3 4 5 NA
11.	Resentment and sorrow make up a good portion of my life.	1 2 3 4 5 NA
12.	Our children and I have become victims of his anger.	1 2 3 4 5 NA
13.	He has needed much attention and encouragement from me.	1 2 3 4 5 NA
14.	Support from the WCB pain management course strengthened me.	1 2 3 4 5 NA
15.	Our pain is gradually healing.	1 2 3 4 5 NA
16.	I feel concerned that my partner denies his physical limitations.	1 2 3 4 5 NA
17.	Fears escalate as pain has not improved with surgery.	1 2 3 4 5 NA
18.	Friends and family could not show compassion for my partner.	1 2 3 4 5 NA
19.	Our love making has been challenged.	1 2 3 4 5 NA
20.	I find that talking and sharing comforts us.	1 2 3 4 5 NA
21.	I've learned patience and compassion for others, especially my partner	1 2 3 4 5 NA
22.	The constant cruel pain takes away from every member of our family.	1 2 3 4 5 NA
23.	I worry about him all the time.	1 2 3 4 5 NA
24.	I get tired more easily now.	1 2 3 4 5 NA
25.	He always thinks I am going to leave him.	1 2 3 4 5 NA
26.	His family and friends stopped asking for help.	1 2 3 4 5 NA
27.	I've started to treat him like a child.	1 2 3 4 5 NA
28.	I now do more things alone.	1 2 3 4 5 NA
29.	It bothers me that I have to get up and go to work and he doesn't..	1 2 3 4 5 NA

30.	I feel guilty for being angry.	1 2 3 4 5 NA
31.	He used to be easy going, now he is bitter.	1 2 3 4 5 NA
32.	I worry about him mixing alcohol with medication.	1 2 3 4 5 NA
33.	I feel that since his injury our life has been put on hold.	1 2 3 4 5 NA
34.	We argue more than we ever did before.	1 2 3 4 5 NA
35.	I worry about his general health.	1 2 3 4 5 NA
36.	The children experience much pressure.	1 2 3 4 5 NA
37.	My emotions and frustrations are bottled up inside me.	1 2 3 4 5 NA
38.	Dealing with WCB put undue stress upon the whole family.	1 2 3 4 5 NA
39.	I've had to learn to do things differently.	1 2 3 4 5 NA
40.	I felt as though we were being judged by WCB.	1 2 3 4 5 NA
41.	The side effects on the family is painful as the pain itself.	1 2 3 4 5 NA
42.	I've had learned to live with pain and effects of necessity.	1 2 3 4 5 NA
43.	I deal with situations as they arise, one day at a time.	1 2 3 4 5 NA
44.	I take comfort in that things could be worse.	1 2 3 4 5 NA
45.	I feel that all the responsibility has fallen on my shoulders.	1 2 3 4 5 NA
46.	I feel very lonely, we now avoid each other.	1 2 3 4 5 NA
47.	I feel like I'm with a stranger who has become a miserable child	1 2 3 4 5 NA
48.	I walk on eggshells, never knowing what to expect.	1 2 3 4 5 NA
49.	I put my feelings on hold until I know what kind of a day he is having.	1 2 3 4 5 NA
50.	I find life is very unstable and full of turmoil.	1 2 3 4 5 NA
51.	Neither of us can find the assistance we need.	1 2 3 4 5 NA
52.	I can't be understanding and supportive anymore.	1 2 3 4 5 NA
53.	I try desperately to handle severe depression.	1 2 3 4 5 NA
54.	I am afraid to leave my partner alone in case of suicide.	1 2 3 4 5 NA
55.	I feel all alone, wanting so badly for some support.	1 2 3 4 5 NA
56.	My sleep pattern is much disturbed.	1 2 3 4 5 NA
57.	My partner is not involved with the children as much.	1 2 3 4 5 NA
58.	When he is in pain, everyone is in pain and suffers.	1 2 3 4 5 NA
59.	My husband is constantly yelling and screaming.	1 2 3 4 5 NA
60.	His loudness creates my constant headaches.	1 2 3 4 5 NA
61.	I take on jobs or activities just to stay away from home.	1 2 3 4 5 NA

62.	He withdrew from us.	1 2 3 4 5 NA
63.	He has left us.	1 2 3 4 5 NA
64.	He is always complaining about the pain.	1 2 3 4 5 NA
65.	It seems as the years go by he is getting worse and worse.	1 2 3 4 5 NA
66.	The worse the pain gets the less the doctors or WCB or anyone will help	1 2 3 4 5 NA
67.	He is spending too much time eating and is getting overweight.	1 2 3 4 5 NA
68.	I find myself fed-up with the whole situation, at times.	1 2 3 4 5 NA
69.	I feel like walking away.	1 2 3 4 5 NA
70.	I feel angry at the system.	1 2 3 4 5 NA

Thank you for your help!

Please return in the enclosed self-addressed envelope.

APPENDIX L

Phase Three Additional Statements

	Additional Statements or Comments
1	When my partner is in pain, I respect this and assist, as do the children.
2	My partner treats pain lightly and tries to exercise, diet and rest.
3	WCB was great! Our only frustration was waiting a full year for surgery.
4	There were times when he laid on the couch for weeks and I had to wash, feed and shave him etc.
5	He couldn't walk. He was waiting for surgery.
6	Since the last surgery there was some improvement.
7	We don't have a sex life.
8	He suffered severe depression.
9	He had to change his whole life style-so did I.
10	Due to the strain of everything regarding his pain and suffering, I could not take anymore and divorced him.
11	It's like getting married without the honeymoon or going on holiday with no money.
12	It is very trying-alot of the responsibilities are now mine, financially, emotionally, maintaining stability, maintaining all the household and raising the children.
13	In my son's first 3 years of life, my husband was unable to give him a bath, as bending over the tub was too painful.
14	Creates limits that are new
15	WCB was the worst for making us feel there was no hope to help us through.
1	We lost alot at the hands of WCB.
6	We ate macaroni and porridge for almost 30 months. We did not have enough to live on.
17	My husband begged on a daily basis for them to help him sop he could go back to work.
18	They treated him and me like dirt anyway.
19	Canmore pain clinic helped alot.
20	We are still trying to catch up after two and a half years.
21	I feel constant stress being financially responsible.
22	I feel fear and uncertainty about our future.
23	I feel I have to take on more work around the house due to his constant pain.

24	Other family members and friends don't understand the severity of the pain.
25	You don't know if he goes to work and will come home with agonizing back pain.
26	I find that since his injury we had to learn how to trust people all over again.
27	Victims of his pain
28	Not guilty of the anger of the pain, but angry at the system
29	I put my activities and plans on hold depending on pain.
30	I feel that WCB has expected me to accept more responsibilities both financially and emotionally.
31	WCB takes too long to get results.
32	It is very frustrating, we don't seem to enjoy things anymore.
33	It appears that WCB and medical doctors don't want anything to do with chronic back pain or perhaps they don't know anything about chronic back pain.
34	WCB tries to make it seem like out fault.
35	Our activities are limited.
36	WCB is more interested in paper than in people.
37	I feel like we are just a number.
38	There is no follow up support once WCB withdraws financial support.
39	Being responsible for running of home, paying bills, shopping.
40	Frustration with WCB when they say he can have light job when B.C. doctors say he can't work. Only doctor that says he can work is WCB doctor.
41	I do wish WCB would be more supportive instead of being so judgmental.
42	The WCB worker doesn't care how much my partner wants to return to work, but keeps pressuring the family because he has stopped my partners benefits.
43	The stress [of WCB} is what is prolonging his improvement.
44	I would love for WCB to live in my shoes for one week, then maybe they would stop being difficult.
45	Have had to work two jobs to support family.
46	I have experienced stress related illness since his injury.
47	My husband's self-esteem is gone. He believes he cannot support the family and feels useless.
48	The financial strain has caused us to lose our home and left us struggling with bills.
49	He does not know what the future hold for job opportunities as his own company seems to have pushed him aside and does not seem to want him back, if he could recover.

50	I feel frustration not sadness because my husband is not able to do everything he would like in his free time.
51	I sometimes forget things aren't the same.
52	He hides his pain because he says there is nothing that can be done about it anyway.
53	The worst! One word Hell!
54	My partner was a guinea pig for WCB doctors. Five surgeries, not one lessened the pain or problem.
55	Not once did WCB or doctors involve me or even talk to me.
56	I was left to deal on my own after they were done using him.
57	I was fearful because I didn't know what they were going to do to him the next time.
58	After all these years, I have learned to deal with the problems (except money problems). I think it is a little late for support services.
59	My own back is not good since I have had to take over doing all the heavy work.
60	Each day is like living in hell.
61	He complains more each day, everything myself and the children do is wrong. He swears at us.
62	All he does is overeat and sit around an complain about everything.
63	We are a very unhappy family with him here.
64	He blames us for his pain everyday. It's not our fault at all.
65	I wish each day for his pain to be gone, but it seems like its getting worse.
66	I have no time for me or anytime or money to spend on me.
67	I find myself doing everything that must be done: manual labour, cook, waiter, taxi driver, gopher, chore boy--even bread winner.
68	Our social life has been put on hold.
69	Financially we have been standing still.
70	Travel is something we only dream about.
71	He is always frustrated, he can't do much around the house.
72	Asking people to help with things is hard.
73	The most difficult thing is his associated chronic depression, from being in constant pain and inability to perform a job for wages.
74	Our financial situation is deteriorating because he cannot get a good paying job that he can actually do.
75	I find it ridiculous and insulting that we are getting no help whatsoever from WCB.
76	I never thought this type of back surgery could destroy a family.

77	WCB has just made our situation worse.
78	I feel we are financially and emotionally depressed.
79	It is pure hell especially since I have chronic low back pain to try to deal with.
80	I try to accept it and be strong and understanding.
81	I put extra stress on myself, as a result I had a heart attack.
82	WCB contributes to my heart attack.
83	My husband has returned to work thanks to the WCB rehab Center. They really helped him get back to work.
84	He is still in pain alot of the time but really doesn't so much about it, so why should we.
85	We are coping very well now and only partake in activities he is comfortable with. WCB pain clinic helped his outlook.
86	I have become more self-sufficient.
87	We have not experienced some of the negative effects as we have good family support and religious background. We have been lucky.
88	We are still struggling, although we do the best we can.
89	I do most of the things with the children.
90	I had surgery on my back six months prior to my husband. We went through therapy together.
91	We lost everything material.
92	We got professional help to save our marriage. We are okay now.
93	WCB is refusing to acknowledge their responsibility in this matter.
94	We do not have the strength left to fight WCB.
95	A lifetime of work and education is lost. Now what?
96	We were not aware that programs were available. We have had little or not therapy or medical follow-up.
97	We all coped. He didn't dwell on it.
98	He very rarely took his frustrations out on the rest of us.
99	We were very supportive, which may have made it easier for him to suffer it out himself.
100	We will do anything possible to avoid becoming involved with WCB again.
101	We got support from WCB only after involving a politician.
102	With medical and family support the physical pain are difficult but manageable.
103	WCB is a big farce to protect the employer.
104	My partner is a fighter and doesn't seek pity. It helps me to have a strong husband.

105	The WCB system is unfair to those who need it and pay for it for years.

APPENDIX M

Phase Three Additional Statements Edit

	Additional Statements or Comments
1	When my partner is in pain, I respect this and assist, as do the children.
2	My partner treats pain lightly and tries to exercise, diet and rest.
3	WCB was great! Our only frustration was waiting a full year for surgery.
4	There were times when he laid on the couch for weeks and I had to wash, feed and shave him etc.
5	He couldn't walk. He was waiting for surgery.
6	Since the last surgery there was some improvement.
8	He suffered severe depression.
10	Due to the strain of everything regarding his pain and suffering, I could not take anymore and divorced him.
17	My husband begged on a daily basis for them to help him sop he could go back to work.
18	They treated him and me like dirt anyway.
19	Canmore pain clinic helped alot.
24	Other family members and friends don't understand the severity of the pain.
25	You don't know if he goes to work and will come home with agonizing back pain.
26	I find that since his injury we had to learn how to trust people all over again.
30	I feel that WCB has expected me to accept more responsibilities both financially and emotionally.
31	WCB takes too long to get results.
32	It is very frustrating, we don't seem to enjoy things anymore.
33	It appears that WCB and medical doctors don't want anything to do with chronic back pain or perhaps they don't know anything about chronic back pain.
36	WCB is more interested in paper than in people.
37	I feel like we are just a number.
38	There is no follow up support once WCB withdraws financial support.
40	Frustration with WCB when they say he can have light job when B.C. doctors say he can't work. Only doctor that says he can work is WCB doctor.
42	The WCB worker doesn't care how much my partner wants to return to work, but keeps pressuring the family because he has stopped my partners benefits.
44	I would love for WCB to live in my shoes for one week, then maybe they would stop being difficult.

45	Have had to work two jobs to support family.
46	I have experienced stress related illness since his injury.
47	My husband's self-esteem is gone. He believes he cannot support the family and feels useless.
50	I feel frustration not sadness because my husband is not able to do everything he would like in his free time.
51	I sometimes forget things aren't the same.
52	He hides his pain because he says there is nothing that can be done about it anyway.
53	The worst! One word Hell!
55	Not once did WCB or doctors involve me or even talk to me.
56	I was left to deal on my own after they were done using him.
57	I was fearful because I didn't know what they were going to do to him the next time.
58	After all these years, I have learned to deal with the problems (except money problems). I think it is a little late for support services.
59	My own back is not good since I have had to take over doing all the heavy work.
63	We are a very unhappy family with him here.
64	He blames us for his pain everyday. It's not our fault at all.
66	I have no time for me or anytime or money to spend on me.
68	Our social life has been put on hold.
70	Travel is something we only dream about.
72	Asking people to help with things is hard.
73	The most difficult thing is his associated chronic depression, from being in constant pain and inability to perform a job for wages.
75	I find it ridiculous and insulting that we are getting no help whatsoever from WCB.
76	I never thought this type of back surgery could destroy a family.
77	WCB has just made our situation worse.
79	It is pure hell especially since I have chronic low back pain to try to deal with.
80	I try to accept it and be strong and understanding.
81	I put extra stress on myself, as a result I had a heart attack.
82	WCB contributes to my heart attack.
83	My husband has returned to work thanks to the WCB rehab Center. They really helped him get back to work.

84	He is still in pain alot of the time but really doesn't so much about it, so why should we.
85	We are coping very well now and only partake in activities he is comfortable with. WCB pain clinic helped his outlook.
86	I have become more self-sufficient.
87	We have not experienced some of the negative effects as we have good family support and religious background. We have been lucky.
88	We are still struggling, although we do the best we can.
90	I had surgery on my back six months prior to my husband. We went through therapy together.
92	We got professional help to save our marriage. We are okay now.
93	WCB is refusing to acknowledge their responsibility in this matter.
94	We do not have the strength left to fight WCB.
95	A lifetime of work and education is lost. Now what?
96	We were not aware that programs were available. We have had little or not therapy or medical follow-up.
97	We all coped. He didn't dwell on it.
98	He very rarely took his frustrations out on the rest of us.
99	We were very supportive, which may have made it easier for him to suffer it out himself.
100	We will do anything possible to avoid becoming involved with WCB again.
101	We got support from WCB only after involving a politician.
102	With medical and family support the physical pain are difficult but manageable.
103	WCB is a big farce to protect the employer.
104	My partner is a fighter and doesn't seek pity. It helps me to have a strong husband.
105	The WCB system is unfair to those who need it and pay for it for years.

APPENDIX N

Fourteen Solution Table

Cluster Items And Bridging Values for Fourteen Solution Table

No.	Cluster /Items	[a]BI
	Cluster 1	
1	I was frustrated because I couldn't do anything about his pain.	.06
3	I was sad because our lives were turned upside down.	.35
24	I get tired more easily now.	.05
28	I now do more things alone.	.05
37	My emotions and frustrations are bottled up inside me.	.08
30	I feel guilty for being angry.	.03
56	My sleep pattern is much disturbed.	.23
55	I feel all alone, wanting so badly for some support.	.03
	Cluster Average	.11
	Cluster 2	
68	I find myself fed-up with the whole situation, at times.	.28
2	I became lonely when we stopped seeing all our friends.	.20
29	It bothers me that I have to get up and go to work and he doesn't.	.09
	Cluster Average	.19
	Cluster 3	
23	I worry about him all the time.	.22
50	I find life is very unstable and full of turmoil.	.26
45	I feel that all the responsibility has fallen on my shoulders.	.17
49	I put my feelings on hold until I know what kind of a day he is having.	.11
53	I try desperately to handle severe depression.	.05
11	Resentment and sorrow make up a good portion of my life.	.05
61	I take on jobs or activities just to stay way from home.	.00
	Cluster Average	.13
	Cluster 4	
43	I deal with situations as they arise, one day at a time.	.35
39	I've had to learn to do things differently.	.26

21	I've learned patience and compassion for others, especially my partner.	.45
42	I have learned to live with pain and effects of it as a matter of necessity.	.34
44	I take comfort in that things could be worse.	.47
20	I find that talking and sharing comfort us.	.57
15	Our pain is gradually healing.	.71
	Cluster Average	.45
	Cluster 5	
35	I worry about his general health.	.24
7	I am embarrassed to watch my husband crawl from point A to B.	.22
27	I've started to treat him like a child.	.20
8	I lost trust in him when he'd steal pain pills.	.25
	Cluster Average	.23
	Cluster 6	
48	I walk on eggshells, never knowing what to expect.	.10
69	I feel like walking away.	.13
46	I feel very lonely, we now avoid each other.	.16
47	I feel like I'm with a stranger who has become a miserable child.	.22
52	I can't be understanding and supportive anymore.	.02
	Cluster Average	.13
	Cluster 7	
16	I feel concerned that my partner denies his physical limitations.	.48
32	I worry about him mixing alcohol with medication.	.29
60	His loudness creates my constant headaches and sleepless nights.	.25
67	He is spending too much time eating and is getting overweight.	.41
54	I am afraid to leave my partner alone in case of suicide.	.38
	Cluster Average	.36
	Cluster 8	
31	He used to be easy going, now he is bitter.	.38
64	He is always complaining about the pain.	.31
59	My husband is constantly yelling and screaming.	.22

25	He always thinks I am going to leave him.	.46
	Cluster Average	.34
	Cluster 9	
4	We did not know what to do.	.47
40	I felt as though we were being judged by WCB.	.66
38	Dealing with WCB put undue stress upon the whole family.	.52
51	Neither of us can find the assistance we need.	.59
66	The worse the pain gets the less the doctors or WCB or anyone will help.	.51
	Cluster Average	.55
	Cluster 10	
5	The situation drained us financially.	.58
6	We had no money to have fun.	.64
	Cluster Average	.61
	Cluster 11	
10	It is difficult to look forward knowing the pain will always be there.	.52
9	The pain is of priority in all aspects of our daily living.	.57
19	Our love making has been challenged.	.76
33	I feel that since his injury our life has been put on hold.	.20
70	I feel angry at the system.	.50
14	Support from the WCB pain management course strengthened me.	1.00
	Cluster Average	.68
	Cluster 12	
65	It seems as the years go by he is getting worse and worse.	.36
58	When he is in pain, everyone is in pain and suffers.	.38
12	Our children and I have become victims of his anger.	.33
62	He withdrew from us.	.40
63	He has left us.	.46
	Cluster Average	.38
	Cluster 13	

41	The side effects on the family is as painful as the pain itself.	.51
22	The constant cruel pain takes away from every member of our family.	.53
36	The children experience much pressure.	.33
57	My partner is not involved with the children as much.	.44
	Cluster Average	.45
	Cluster 14	
17	Fears escalate as pain has not improved with surgery.	.38
13	He has needed much attention and encouragement from me.	.32
26	His family and friends stop asking for help.	.35
34	We argue more than we ever did before.	.43
18	Friends and family could not show compassion for my partner.	.30
	Cluster Average	.36

[a]BI=Bridging Index

APPENDIX O

Ten Solution Table

Cluster Items And Bridging Values for Ten Solution Table

No.	Cluster /Items	[a]BI
	Cluster 1	
1	I was frustrated because I couldn't do anything about his pain.	.06
3	I was sad because our lives were turned upside down.	.35
24	I get tired more easily now.	.05
28	I now do more things alone.	.05
37	My emotions and frustrations are bottled up inside me.	.08
30	I feel guilty for being angry.	.03
56	My sleep pattern is much disturbed.	.23
55	I feel all alone, wanting so badly for some support.	.03
	Cluster Average	.11
	Cluster 2	
23	I worry about him all the time.	.22
68	I find myself fed-up with the whole situation, at times.	.28
50	I find life is very unstable and full of turmoil.	.26
45	I feel that all the responsibility has fallen on my shoulders.	.17
2	I became lonely when we stopped seeing all our friends.	.20
49	I put my feelings on hold until I know what kind of a day he is having.	.11
53	I try desperately to handle severe depression.	.05
11	Resentment and sorrow make up a good portion of my life.	.05
29	It bothers me that I have to get up and go to work and he doesn't.	.09
61	I take on jobs or activities just to stay way from home.	.00
	Cluster Average	.14
	Cluster 3	
43	I deal with situations as they arise, one day at a time.	.35
39	I've had to learn to do things differently.	.26
21	I've learned patience and compassion for others, especially my partner.	.45
42	I have learned to live with pain and effects of it as a matter of necessity.	.34
44	I take comfort in that things could be worse.	.47
20	I find that talking and sharing comfort us.	.57
15	Our pain is gradually healing.	.71

	Cluster Average	.45
	Cluster 4	
35	I worry about his general health.	.24
48	I walk on eggshells, never knowing what to expect.	.10
7	I am embarrassed to watch my husband crawl from point A to B.	.22
27	I've started to treat him like a child.	.20
69	I feel like walking away.	.13
46	I feel very lonely, we now avoid each other.	.16
47	I feel like I'm with a stranger who has become a miserable child.	.22
8	I lost trust in him when he'd steal pain pills.	.25
52	I can't be understanding and supportive anymore.	.02
	Cluster Average	.17
	Cluster 5	
31	He used to be easy going, now he is bitter.	.38
16	I feel concerned that my partner denies his physical limitations.	.48
64	He is always complaining about the pain.	.31
32	I worry about him mixing alcohol with medication.	.29
59	My husband is constantly yelling and screaming.	.22
25	He always thinks I am going to leave him.	.46
60	His loudness creates my constant headaches and sleepless nights.	.25
67	He is spending too much time eating and is getting overweight.	.41
54	I am afraid to leave my partner alone in case of suicide.	.38
	Cluster Average	.35
	Cluster 6	
4	We did not know what to do.	.47
40	I felt as though we were being judged by WCB.	.66
5	The situation drained us financially.	.58
6	We had no money to have fun.	.64
38	Dealing with WCB put undue stress upon the whole family.	.52
51	Neither of us can find the assistance we need.	.59
66	The worse the pain gets the less the doctors or WCB or anyone will help.	.51
	Cluster Average	.57

	Cluster 7	
10	It is difficult to look forward knowing the pain will always be there.	.52
9	The pain is of priority in all aspects of our daily living.	.57
19	Our love making has been challenged.	.76
33	I feel that since his injury our life has been put on hold.	.20
70	I feel angry at the system.	.50
14	Support from the WCB pain management course strengthened me.	1.00
	Cluster Average	.68
	Cluster 8	
65	It seems as the years go by he is getting worse and worse.	.36
58	When he is in pain, everyone is in pain and suffers.	.38
12	Our children and I have become victims of his anger.	.33
62	He withdrew from us.	.40
63	He has left us.	.46
	Cluster Average	.38
	Cluster 9	
41	The side effects on the family is as painful as the pain itself.	.51
22	The constant cruel pain takes away from every member of our family.	.53
36	The children experience much pressure.	.33
57	My partner is not involved with the children as much.	.44
	Cluster Average	.45
	Cluster 10	
17	Fears escalate as pain has not improved with surgery.	.38
13	He has needed much attention and encouragement from me.	.32
26	His family and friends stop asking for help.	.35
34	We argue more than we ever did before.	.43
18	Friends and family could not show compassion for my partner.	.30
	Cluster Average	.36

[a]BI=Bridging Index

APPENDIX P

Nine Solution Table

Cluster Items And Bridging Values for Nine Solution Table

No.	Cluster /Items	[a]BI
	Cluster 1	
1	I was frustrated because I couldn't do anything about his pain.	.06
3	I was sad because our lives were turned upside down.	.35
24	I get tired more easily now.	.05
28	I now do more things alone.	.05
37	My emotions and frustrations are bottled up inside me.	.08
30	I feel guilty for being angry.	.03
56	My sleep pattern is much disturbed.	.23
55	I feel all alone, wanting so badly for some support.	.03
	Cluster Average	.11
	Cluster 2	
23	I worry about him all the time.	.22
68	I find myself fed-up with the whole situation, at times.	.28
50	I find life is very unstable and full of turmoil.	.26
45	I feel that all the responsibility has fallen on my shoulders.	.17
2	I became lonely when we stopped seeing all our friends.	.20
49	I put my feelings on hold until I know what kind of a day he is having.	.11
53	I try desperately to handle severe depression.	.05
11	Resentment and sorrow make up a good portion of my life.	.05
29	It bothers me that I have to get up and go to work and he doesn't.	.09
61	I take on jobs or activities just to stay way from home.	.00
	Cluster Average	.14
	Cluster 3	
43	I deal with situations as they arise, one day at a time.	.35
39	I've had to learn to do things differently.	.26
21	I've learned patience and compassion for others, especially my partner.	.45
42	I have learned to live with pain and effects of it as a matter of necessity.	.34
44	I take comfort in that things could be worse.	.47

20	I find that talking and sharing comfort us.	.57
15	Our pain is gradually healing.	.71
	Cluster Average	.45
	Cluster 4	
35	I worry about his general health.	.24
48	I walk on eggshells, never knowing what to expect.	.10
7	I am embarrassed to watch my husband crawl from point A to B.	.22
27	I've started to treat him like a child.	.20
69	I feel like walking away.	.13
46	I feel very lonely, we now avoid each other.	.16
47	I feel like I'm with a stranger who has become a miserable child.	.22
8	I lost trust in him when he'd steal pain pills.	.25
52	I can't be understanding and supportive anymore.	.02
	Cluster Average	.17
	Cluster 5	
31	He used to be easy going, now he is bitter.	.38
16	I feel concerned that my partner denies his physical limitations.	.48
64	He is always complaining about the pain.	.31
32	I worry about him mixing alcohol with medication.	.29
59	My husband is constantly yelling and screaming.	.22
25	He always thinks I am going to leave him.	.46
60	His loudness creates my constant headaches and sleepless nights.	.25
67	He is spending too much time eating and is getting overweight.	.41
54	I am afraid to leave my partner alone in case of suicide.	.38
	Cluster Average	.35
	Cluster 6	
4	We did not know what to do.	.47
40	I felt as though we were being judged by WCB.	.66
5	The situation drained us financially.	.58
6	We had no money to have fun.	.64
38	Dealing with WCB put undue stress upon the whole family.	.52

51	Neither of us can find the assistance we need.	.59
66	The worse the pain gets the less the doctors or WCB or anyone will help.	.51
	Cluster Average	.57
	Cluster 7	
10	It is difficult to look forward knowing the pain will always be there.	.52
9	The pain is of priority in all aspects of our daily living.	.57
19	Our love making has been challenged.	.76
33	I feel that since his injury our life has been put on hold.	.20
70	I feel angry at the system.	.50
14	Support from the WCB pain management course strengthened me.	1.00
	Cluster Average	.68
	Cluster 8	
41	The side effects on the family is as painful as the pain itself.	.51
22	The constant cruel pain takes away from every member of our family.	.53
65	It seems as the years go by he is getting worse and worse.	.36
58	When he is in pain, everyone is in pain and suffers.	.38
36	The children experience much pressure.	.33
12	Our children and I have become victims of his anger.	.33
57	My partner is not involved with the children as much.	.44
62	He withdrew from us.	.40
63	He has left us.	.46
	Cluster Average	.41
	Cluster 9	
17	Fears escalate as pain has not improved with surgery.	.38
13	He has needed much attention and encouragement from me.	.32
26	His family and friends stop asking for help.	.35
34	We argue more than we ever did before.	.43
18	Friends and family could not show compassion for my partner.	.30
	Cluster Average	.36

[a]BI=Bridging Index

APPENDIX Q

Eight Solution Map

Cluster Items And Bridging Values for Eight Solution Map

No.	Cluster /Items	[a]BI
	Cluster 1	
1	I was frustrated because I couldn't do anything about his pain.	.06
3	I was sad because our lives were turned upside down.	.35
24	I get tired more easily now.	.05
28	I now do more things alone.	.05
37	My emotions and frustrations are bottled up inside me.	.08
30	I feel guilty for being angry.	.03
56	My sleep pattern is much disturbed.	.23
55	I feel all alone, wanting so badly for some support.	.03
	Cluster Average	.11
	Cluster 2	
23	I worry about him all the time.	.22
68	I find myself fed-up with the whole situation, at times.	.28
50	I find life is very unstable and full of turmoil.	.26
45	I feel that all the responsibility has fallen on my shoulders.	.17
2	I became lonely when we stopped seeing all our friends.	.20
49	I put my feelings on hold until I know what kind of a day he is having.	.11
53	I try desperately to handle severe depression.	.05
11	Resentment and sorrow make up a good portion of my life.	.05
29	It bothers me that I have to get up and go to work and he doesn't.	.09
61	I take on jobs or activities just to stay way from home.	.00
	Cluster Average	.14
	Cluster 3	
43	I deal with situations as they arise, one day at a time.	.35
39	I've had to learn to do things differently.	.26
21	I've learned patience and compassion for others, especially my partner.	.45
42	I have learned to live with pain and effects of it as a matter of necessity.	.34
44	I take comfort in that things could be worse.	.47

20	I find that talking and sharing comfort us.	.57
15	Our pain is gradually healing.	.71
	Cluster Average	.45
	Cluster 4	
35	I worry about his general health.	.24
48	I walk on eggshells, never knowing what to expect.	.10
7	I am embarrassed to watch my husband crawl from point A to B.	.22
27	I've started to treat him like a child.	.20
69	I feel like walking away.	.13
46	I feel very lonely, we now avoid each other.	.16
47	I feel like I'm with a stranger who has become a miserable child.	.22
8	I lost trust in him when he'd steal pain pills.	.25
52	I can't be understanding and supportive anymore.	.02
	Cluster Average	.17
	Cluster 5	
31	He used to be easy going, now he is bitter.	.38
16	I feel concerned that my partner denies his physical limitations.	.48
64	He is always complaining about the pain.	.31
32	I worry about him mixing alcohol with medication.	.29
59	My husband is constantly yelling and screaming.	.22
25	He always thinks I am going to leave him.	.46
60	His loudness creates my constant headaches and sleepless nights.	.25
67	He is spending too much time eating and is getting overweight.	.41
54	I am afraid to leave my partner alone in case of suicide.	.38
	Cluster Average	.35
	Cluster 6	
4	We did not know what to do.	.47
40	I felt as though we were being judged by WCB.	.66
5	The situation drained us financially.	.58
6	We had no money to have fun.	.64
38	Dealing with WCB put undue stress upon the whole family.	.52

51	Neither of us can find the assistance we need.	.59
66	The worse the pain gets the less the doctors or WCB or anyone will help.	.51
	Cluster Average	.57
	Cluster 7	
10	It is difficult to look forward knowing the pain will always be there.	.52
9	The pain is of priority in all aspects of our daily living.	.57
19	Our love making has been challenged.	.76
33	I feel that since his injury our life has been put on hold.	.20
70	I feel angry at the system.	.50
14	Support from the WCB pain management course strengthened me.	1.00
	Cluster Average	.68
	Cluster 8	
17	Fears escalate as pain has not improved with surgery.	.38
13	He has needed much attention and encouragement from me.	.32
41	The side effects on the family is as painful as the pain itself.	.51
22	The constant cruel pain takes away from every member of our family.	.53
65	It seems as the years go by he is getting worse and worse.	.36
58	When he is in pain, everyone is in pain and suffers.	.38
36	The children experience much pressure.	.33
12	Our children and I have become victims of his anger.	.33
26	His family and friends stop asking for help.	.35
34	We argue more than we ever did before.	.43
57	My partner is not involved with the children as much.	.44
18	Friends and family could not show compassion for my partner.	.30
62	He withdrew from us.	.40
63	He has left us.	.46
	Cluster Average	.39

[a]BI=Bridging Index

APPENDIX R

Impact Severity by Participant

Ranked Mean by Survey Participant

Rank	ID	Mean
1	35	4.59
2	51	4.41
3	44	4.39
4	4	4.32
5	23	4.32
6	66	4.24
7	52	4.18
8	32	4.16
9	39	4.13
10	45	3.99
11	43	3.98
12	71	3.95
13	29	3.93
13	67	3.88
15	40	3.88
16	11	3.84
17	31	3.78
18	47	3.76
19	60	3.75
20	36	3.72
21	76	3.70
22	26	3.67
23	58	3.67
24	18	3.65
25	33	3.61
26	64	3.59
27	5	3.58
28	62	3.58
29	8	3.57

30	28	3.53
31	63	3.45
32	21	3.42
33	19	3.41
34	22	3.38
35	9	3.35
36	41	3.31
37	50	3.25
38	17	3.18
39	27	3.17
40	77	3.14
41	25	3.14
42	14	3.13
43	49	3.12
44	37	3.00
45	13	2.97
46	16	2.96
47	6	2.96
48	34	2.94
49	68	2.94
50	42	2.93
51	48	2.92
52	73	2.86
53	56	2.83
54	3	2.72
55	74	2.70
56	20	2.66
57	69	2.64
58	54	2.58
59	59	2.53
60	65	2.45
61	15	2.41
62	53	2.38
63	24	2.33

64	67	2.27
65	1	2.22
66	61	2.12
67	70	1.81
68	12	1.79
69	2	1.72
70	57	1.72
71	55	1.71

APPENDIX S

Statement Ranks by Descending Means and Percent Agreement

	Statement		Percent Endorsing Each Value						Mean	% Agree
			1*	2	3	4	5	NA		
1	1	I was frustrated because I couldn't do anything about his pain.	1	1	6	14	76	1	4.64	96
2	10	It is difficult to look forward knowing the pain will always be there.	1	3	16	17	61	1	4.36	94
3	4	We did not know what to do.	4	3	11	13	64	5	4.36	88
4	17	Fears escalate as pain has not improved with surgery.	0	7	7	7	39	41	4.30	53
5	40	I felt as though we were being judged by WCB.	7	7	7	10	68	1	4.26	85
6	23	I worry about him all the time.	3	7	16	11	63	0	4.25	90
7	35	I worry about his general health.	1	9	14	16	61	0	4.25	91
8	3	I was sad because our lives were turned upside down.	3	4	14	24	55	0	4.24	93
9	9	The pain is of priority in all aspects of our daily living.	4	10	6	21	58	1	4.20	85
10	13	He has needed much attention and encouragement from me.	1	7	16	24	51	1	4.17	91
11	5	The situation drained us financially.	7	7	4	23	52	7	4.14	79
12	19	Our love making has been challenged.	3	11	14	18	52	1	4.07	84
13	14	Support from the WCB pain management course strengthened me.	4	4	3	4	27	55	4.07	11
14	6	We had no money to have fun.	6	7	13	18	49	6	4.06	80
15	38	Dealing with WCB put undue stress upon the whole family.	11	7	11	7	61	3	4.01	79
16	33	I feel that since his injury our life has been put on hold.	4	14	11	13	51	7	3.99	75

17	41	The side effects on the family is as painful as the pain itself.	6	11	16	17	49	1	3.94	82
18	70	I feel angry at the system.	16	4	7	14	54	5	3.91	75
19	22	The constant cruel pain takes away from every member of our family.	4	17	13	17	48	0	3.89	78
20	68	I find myself fed-up with the whole situation, at times.	9	11	18	18	35	7	3.66	71
21	65	It seems as the years go by he is getting worse and worse.	9	14	17	16	38	4	3.65	71
22	50	I find life is very unstable and full of turmoil.	9	13	24	10	41	4	3.65	75
23	51	Neither of us can find the assistance we need.	11	13	13	14	39	8	3.64	66
24	24	I get tired more easily now.	4	20	16	20	34	8	3.64	70
25	58	When he is in pain, everyone is in pain and suffers.	13	10	20	14	41	3	3.62	75
26	28	I now do more things alone.	11	13	16	18	37	5	3.60	71
27	37	My emotions and frustrations are bottled up inside me.	11	17	13	16	39	4	3.57	68
28	31	He used to be easy going, now he is bitter.	11	7	27	16	34	0	3.57	77
29	36	The children experience much pressure.	7	17	17	13	34	12	3.57	64
30	45	I feel that all the responsibility has fallen on my shoulders.	7	17	21	21	32	1	3.56	74
31	66	The worse the pain gets the less the doctors or WCB or anyone will help.	13	20	11	10	38	6	3.45	59
32	16	I feel concerned that my partner denies his physical limitations.	13	10	20	21	27	10	3.44	68
33	12	Our children and I have become victims of his anger.	17	9	17	17	31	9	3.41	65
34	49	I put my feelings on hold until I know what kind of a day he is having.	12	17	16	13	30	5	3.37	59
35	2	I became lonely when we stopped seeing all our friends.	7	11	27	20	17	17	3.35	64
36	30	I feel guilty for being angry.	13	16	17	13	28	14	3.33	58

37	56	My sleep pattern is much disturbed.	14	16	17	14	28	10	3.30	59
38	64	He is always complaining about the pain.	13	17	25	17	25	1	3.26	67
39	26	His family and friends stop asking for help.	9	20	21	16	20	16	3.22	57
40	34	We argue more than we ever did before.	11	30	16	10	28	5	3.15	54
41	15	Our pain is gradually healing.	10	23	24	21	16	8	3.11	57
42	48	I walk on eggshells, never knowing what to expect.	17	20	21	14	23	5	3.06	58
43	57	My partner is not involved with the children as much.	17	17	17	16	20	13	3.05	53
44	53	I try desperately to handle severe depression.	17	17	18	11	20	17	3.00	49
45	11	Resentment and sorrow make up a good portion of my life.	24	13	18	16	20	8	2.94	54
46	62	He withdrew from us.	23	18	17	17	14	10	2.79	48
47	18	Friends and family could not show compassion for my partner.	24	24	13	16	19	7	2.79	48
48	29	It bothers me that I have to get up and go to work and he doesn't.	24	11	11	7	17	30	2.74	35
49	7	I am embarrassed to watch my husband crawl from point A to B.	17	24	10	7	16	23	2.73	33
50	55	I feel all alone, wanting so badly for some support.	27	14	21	10	17	10	2.73	48
51	32	I worry about him mixing alcohol with medication.	23	6	4	3	16	47	2.67	23
52	59	My husband is constantly yelling and screaming.	24	20	24	7	14	10	2.64	45
53	69	I feel like walking away.	35	17	16	6	16	10	2.43	38
54	46	I feel very lonely, we now avoid each other.	31	21	14	10	10	13	2.38	34
55	27	I've started to treat him like a child.	31	24	16	11	9	10	2.36	36
56	8	I lost trust in him when he'd steal pain pills.	16	10	4	4	6	58	2.36	14

57	47	I feel like I'm with a stranger who has become a miserable child.	28	27	17	6	10	12	2.34	33
58	25	He always thinks I am going to leave him.	38	11	14	10	9	18	2.30	33
59	52	I can't be understanding and supportive anymore.	34	30	11	11	7	7	2.28	29
60	20	I find that talking and sharing comfort us.	34	23	27	11	3	1	2.25	84
61	60	His loudness creates my constant headaches	32	18	16	4	7	21	2.16	27
62	61	I take on jobs or activities just to stay way from home.	34	23	11	7	7	17	2.16	25
63	67	He is spending too much time eating and is getting overweight.	25	32	16	3	6	14	2.16	25
64	44	I take comfort in that things could be worse.	44	28	16	7	6	0	2.03	88
65	54	I am afraid to leave my partner alone in case of suicide.	47	9	7	4	10	23	1.98	21
66	42	I have learned to live with pain and its effects as a matter of necessity.	39	28	18	6	1	3	1.94	85
67	21	I've learned patience and compassion for others, especially my partner.	47	25	18	6	1	3	1.87	90
68	39	I've had to learn to do things differently.	47	27	20	6	0	1	1.84	94
69	43	I deal with situations as they arise, one day at a time.	54	28	14	0	4	0	1.73	96
70	63	He has left us.	35	4	3	0	4	49	1.58	7

*1=strongly disagree, 2= disagree, 3=slightly agree, 4=agree, 5=strongly agree

APPENDIX T

Impact Severity by Demographic Variables

Impact Severity by 3 levels of Pain Severity

Gp. No.	Values	Mean	F Ratio	Prob.	Group Differences
1	Mild (1-7)	2.75	8.87	.0004	Difference between
2	Moderate (8)	3.17			group 3 and group 1
3	Severe (9, 10)	3.59			
	Total	3.23			

Impact Severity by Children

1	No children	3.00	2.86	.0951	No difference
2	Children	3.32			between groups
	Total	3.24			

Impact Severity by Time in Pain

1	1-36 months	2.82	4.07	.0218	Difference between
2	37-120 months	3.34			group 2 and group 1
3	121-480 months	3.44			
	Total	3.22			